

TOO YOUNG TO BE ILL...

A Practical Survival Guide for Caregivers of Children and Young Adults



TOO YOUNG TO BE ILL...

**A Practical Survival Guide for Caregivers of
Children and Young Adults**

Prepared by Patient Advocate Foundation

ACKNOWLEDGEMENTS

Too Young To Be Ill...A Practical Survival Guide for Caregivers of Children and Young Adults has been prepared by the **Patient Advocate Foundation**, a national network for healthcare reform and patient services headquartered in Newport News, Virginia.

Patient Advocate Foundation would like to acknowledge the U.S. Department of Labor, the Social Security Administration and the Centers for Medicare and Medicaid for providing guidance through local and national resources, websites and publications. Patient Advocate Foundation would also like to extend extreme gratitude to Courtney Jones, Peggy Rochon and Michelle Shanks, case managers at the Patient Advocate Foundation, for their time and effort providing insight into this publication as well as Rocquel Robinson for assisting with the creation of the Resource Appendix.

Nancy Davenport-Ennis
President and CEO
Patient Advocate Foundation and
National Patient Advocate Foundation

Beth Darnley, Senior Editor
Chief Program Officer
Patient Advocate Foundation

Principal Writing:

Connie Slayton, BSN
PAF Program Director
2007 Publication Committee
Co-Chair
Patient Advocate Foundation

Mary Giguere, RN, BSN
Director, Colorectal CareLine
2007 Publications Committee
Co-Chair
Patient Advocate Foundation

Constance Goodman, RN
Patient Services Administrator
Patient Advocate Foundation

Tami Lewis, RN
Senior Case Manager
Patient Advocate Foundation

Tanya Walker, RN, BSN
Senior Clinical Case Manager
Patient Advocate Foundation

Ryan Clore
Co-Pay Relief Application Specialist
Patient Advocate Foundation

Contributing Editor:

L. Alan Richardson
Executive VP of Resource
Development
Patient Advocate Foundation

Introduction

This guide was written in response to the many issues that have been identified by the Patient Advocate Foundation (PAF), as we have assisted millions of patients and caregivers across the United States who were faced with illnesses and subsequent access difficulties. Many of those patients and caregivers who found themselves trapped in a maze of access issues, financial worries and emotional strain could have benefited from the preemptive information contained in a comprehensive guide to navigating the healthcare system. No matter what the diagnosis, the process of getting the best for your young patient is rife with red tape and confusion. When confronted with a life threatening illness the more information you have, the more capable you will be to make decisions that can ultimately impact your young patient's healthcare, long term insurability and financial stability. It is our hope that *Too Young To Be Ill... A Practical Survival Guide for Caregivers of Children and Young Adults* will provide you with the necessary tools to anticipate the steps you need to take to make your family's healthcare journey problem free.

There are ten chapters in *Too Young To Be Ill... A Practical Survival Guide for Caregivers of Children and Young Adults* as well as a Resource Appendix at the end to assist you in finding available resources based on the following topics:

Chapter 1: *Diagnosis Day*

Diagnosis Day defines the term diagnosis and provides insight into where to begin upon learning that a young patient has been diagnosed with a life-threatening illness.

Chapter 2: *Why Me?*

Why Me addresses the mental preparation needed for caregivers to cope with life altering changes and how to access the support systems available to you throughout this journey.

Chapter 3: *The Ins and Outs of the Disability Process*

The Ins and Outs of the Disability Process describes the types of disability insurance available, how to navigate the disability process when filing on behalf of your young patient and how this coverage could impact future insurability.

Chapter 4: *Insurance...What are my Options?*

Insurance...What are my Options explains the various types of health insurance plans and explores ways to maintain benefits during an illness.

Chapter 5: *Access to Care Issues for the Pediatric and Young Adult Populations*

Access to Care Issues for the Pediatric and Young Adult Populations explains ways to ensure that your young patient receives the best care available without interruptions.

Chapter 6: *The Importance of Keeping Reliable Medical Records*

The Importance of Keeping Reliable Medical Records stresses the need for documentation so that your young patient will have this information readily available as they return to good health and move into a position of independent control of their long-term healthcare.

Chapter 7: *Preparing for the Possibility of Financial Burdens*

Preparing for the Possibility of Financial Burdens is designed to provide the caregiver with the necessary information to remain financially stable while facing a loved one's illness.

Chapter 8: *Respite Care...Take Advantage!*

Respite Care...Take Advantage lists the primary goals of respite care and how to access this important resource for caregivers.

Chapter 9: *The Early Intervention System...What is it and How can it benefit my Child?*

The Early Intervention System...What is it and How can it benefit my Child explains the early intervention system and how the caregiver can access these services for their child.

Chapter 10: *Cancer and Fertility: A Forgotten Concern for Today's Young Survivors*

Cancer and Fertility: A Forgotten Concern for Today's Young Survivors addresses fertility preservation and body image issues facing young patients.

Chapter 1

Diagnosis Day

Today you became the caregiver of a young patient diagnosed with a chronic and/or life threatening condition. How is this possible? What exactly does having a “diagnosis” entail?

In medicine, diagnosis or diagnostics is the process of identifying a medical condition or disease by its signs, symptoms and from the results of various diagnostic procedures.

Typically, we consult a physician when we have abnormal symptoms. Your physician will then obtain a history of the young person’s illness and examine him/her for signs of disease. The physician may conduct further testing to confirm a diagnosis before providing treatment. Medical tests commonly performed include measuring blood pressure, checking the pulse rate, listening to the heart with a stethoscope, urine tests, stool tests, saliva tests, blood tests, medical imaging, electrocardiogram, hydrogen breath test and, occasionally, biopsy.

An acute illness may be serious but can be diagnosed, treated, and resolved somewhat quickly. A chronic illness continues long after a diagnosis is made. There are many different types of pediatric chronic illnesses that may continue into young adulthood. Some are very serious and require frequent follow up, monitoring, and repeated hospitalizations. Most, however, require regular follow up and occasional hospitalizations, but allow the young patient and family to lead a very normal and productive life.

If you are the caregiver of a young patient newly diagnosed with a chronic illness you may feel overwhelmed with new responsibilities and may not know where to start. Never be afraid to ask questions or seek a second medical opinion as you will become the primary advocate for your young patient in times of critical illness. Make sure you receive and explore all treatment options. Locate the best hospital and physicians for treatment of your young patient once a definitive diagnosis has been rendered. The more you learn about the diagnosis and illness, and the more information you have, the more in control you will feel. Many resources are available to you such as:

- Local or hospital libraries for books or lists of professional organizations
- Support groups
- Reliable internet websites
- Healthcare professionals
- Advocacy Organizations

As you begin to adjust to the day-to-day management of your young patient's illness, you will find that things you thought were impossible might very well be accomplished. Over time you will learn to cope with the new challenges of managing your young patient's illness. With appropriate, sustained support you and your young patient will overcome the challenges thrust upon you by the illness.

Chapter 2

Why Me?

You will quickly find that being a caregiver of a young, sick patient will require a tremendous amount of your time and effort and may prove to be extremely draining, both physically and mentally. You need to make sure you are mentally prepared for any road block that may face you during this difficult time. Furthermore, you must make certain that your young patient is prepared for the challenges that may lie ahead.

Your behavior influences your young patient's overall recovery process and well-being

Most people are not aware that the state of mind of a young patient is a reflection of the caregivers' overall morale. According to the Journal of Child Psychology, Psychiatry and Allied Disciplines, young patients who self-reported poorer quality of life had primary caregivers who were more depressed. It also found that caregivers who reported poorer quality of life for their young patient also reported more illness stressors and perceived their young patient as being more susceptible to illness. This suggests not only a similarity between the caregiver and young patient's mental health; but that the young patient's mental well-being genuinely affects their ability to fight the physical illness.

Since the caregiver's morale is such an important determining factor of a young patient's wellness, it is extremely important that the young patient does not perceive that you are anything less than optimistic about their outcome. It is important that the young patient has hope, and hope begins with you.

How to effectively maintain a positive attitude in difficult times

In order to provide your loved one with the proper care, it is essential that you have a strong positive attitude. Remaining positive when someone who is dependent upon you that is chronically ill is a tremendous challenge. We have outlined some suggestions below that you may find beneficial.

- **Be prepared for the lows.** You will have many days in which producing a smile will seem difficult. Learning to accept a loved one's diagnosis often leads to anger, fear, and/or depression, which are natural feelings that caregivers face. Even though dealing with these emotions is a natural progression, you do not need to feel as if you should let yourself suffer alone.
- **Seek counseling.** It is important that you talk about your feelings. Being mentally healthy does not mean that you bottle up the natural feelings of depression and anger; instead, face these emotions head on. Talking about these feelings with a skilled listener will assist you in learning how to cope with your grief and work through your emotions in a more natural process.
- **Seek out as many support systems as possible.** Do not be afraid to let others help you; furthermore, do not be scared to ask for help! The more people acting on behalf of your young patient, the less strain there will be on you. Communicate with your family and friends regarding the ways they can help you with your daily obligations. You might also find it useful to seek out national and/or local non-profit organizations that offer support counseling. There are also many peer support groups available to assist your young patient as they struggle to process their feelings about their illness. Many caregivers and patients also find comfort from faith-based organizations. Various support organizations are located in the Resource Appendix at the end of this guide.
- **Educate yourself as much as you can about your young patient's illness.** Learning about your loved one's illness properly prepares you to ask the appropriate questions, understand various treatments they may receive, and helps you effectively relay your knowledge of the illness to the young patient. Making certain that they understand what they are going through will help mentally prepare them for the challenges to come. Organizations such as the American Cancer Society and the National Cancer Institute are viable entities that may assist you with information regarding your young patient's illness. Educational resources are located in the Resource Appendix at the end of this guide.

Challenge yourself to remain positive, exhibit a sense of humor and focus on cherishing the good times you share with your young patient during this difficult period. Approach each challenge as if it is simply a stepping stone to the next stage of your lives. Your emotional state, and more importantly, your young patient's emotional state, may serve as the determining factor in setting the tone for your young patient's recovery.

Chapter 3

The Ins and Outs of the Disability Process

Whether you are filing a claim through an individual disability insurance policy or through the Social Security Administration, the process can be confusing and laborious. Achieving success with the disability approval process is imperative as it can ultimately impact your young patient's long-term insurability and financial stability. It is our hope that the information provided below will help you decide if your young patient might be eligible for Social Security Disability Income (SSDI) or Supplemental Security Income (SSI) as well as providing you with the necessary tools to anticipate the steps you will need to take in order to make your disability claim process problem free.

Caregivers of children under age 18 who have disabilities may be eligible for SSI payments as well as adults who became disabled in childhood before the age of 22 and who might be entitled to SSDI benefits. This SSDI benefit is called a "child's" benefit as it is paid based on a caregiver's Social Security earnings record.

Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) Defined

SSDI is a federal disability insurance program designed for individuals who have worked enough to earn sufficient "work credits". Under this program monthly payments are based on the individual's earning record, which is on file with the Social Security Administration.

SSI is a federal financial assistance program which provides monthly payments to individuals who have either never worked or have insufficient credits on their earnings record to qualify for SSDI. SSI recipients are typically required to have limited financial resources and assets that do not exceed \$2,000.00.

These programs are administered by the Social Security Administration and the disability criteria are the same for both. In order to qualify for SSI or SSDI, an individual must have impairment or a combination of impairments that preclude substantial gainful work activity that is expected to last a continuous period of 12 months or longer or that is expected to result in death.

SSI makes monthly payments to people with low incomes and limited resources who are 65 or older, or blind or disabled. Your young patient can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. The amount of SSI payments is different from one state to another because some states contribute to the SSI payment. Your local Social Security office can tell you more about your state's SSI payment.

When SSI is decided by Social Security, your young patient's income and resources are taken into consideration. The income and resources of family members living in the household are also taken into consideration. These rules apply if your young patient is currently residing at home. They also apply if he or she is away at school, but returns home from time to time and is subject to your control. If your young patient's income and resources, and the income and resources of family members living in the household are more than the amount allowed, the SSI application would be denied.

Your young patient must meet all of the following requirements to be considered disabled and therefore eligible for SSI.

- The young patient must not be working and earning more than \$900 a month in 2007, which does change annually.
- The young patient must have a physical or mental condition, or a combination of conditions, that result in "marked and severe functional limitations." The conditions must severely limit daily activities.
- The young patient's condition must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.

If the young patient's conditions results in "marked and severe functional limitations, he or she would be considered disabled. However, if it does not result in those limitations, or does not last for 12 months, your young patient would not be deemed disabled.

What happens when your young patient turns 18?

For disability purposes in the SSI program, a child becomes an adult

at age 18, and different medical and non-medical rules apply when deciding if an adult can receive SSI disability payments. For example, Social Security will not count the income and resources of family members when deciding whether an adult meets the financial limits for SSI. Only the income and resources of the young patient would be taken into consideration.

If your young patient is already receiving SSI payments, the medical condition will be reviewed once he or she reaches their eighteenth birthday. The adult disability rules will be used to determine eligibility once this milestone occurs. If your young patient was not eligible for SSI before his or her eighteenth birthday because you, the caregiver, exceeded the income or resources criteria, he or she may now become eligible for SSI at age 18.

SSDI benefits for adults disabled since childhood prior to age 22

The SSDI program pays benefits to adults who have a disability that began before they became 22 years old. Social Security considers this a child's benefit because it is paid based on a caregiver's Social Security earnings resources. For a disabled adult to become entitled to this "child" benefit, one of his or her caregivers:

- Must be receiving Social Security retirement or disability benefits; or
- Must have died and have worked long enough under Social Security.

These benefits are also payable to an adult who received dependent's benefits on a caregiver's Social Security earnings record prior to age 18, if he or she is disabled at age 18. The SSDI disabled adult "child" benefits continue as long as the individual remains disabled. Your young patient does not need to have worked to qualify for these benefits.

Steps for an expedient disability application

The challenge for patients who are diagnosed with progressive diseases, such as early stage cancer, is that upon initial application their condition may not meet the Social Security disability requirements. A patient may expect to undergo surgery, with an estimated recovery

time of six weeks, and then complete a chemotherapy regimen which lasts for six months with the hope that at this point the disease will have been eradicated and the patient can return to normal activities. Unfortunately, how a disease progresses is not predictable nor is a patient's ability to tolerate certain treatments or therapies, which leaves many patients with no access to disability income, or the subsequent health coverage benefits, during a crucial time in their lives.

There are certain steps that you can take to ensure a smoother and more expedient application and approval process. We have provided a list of tips below:

- Apply for SSDI/SSI benefits as soon as a critical diagnosis is rendered
- When you go to apply for benefits, take a copy of your medical records and a letter of support from your physician as well as a copy of the patient's birth certificate
- Bring a list of medications that the patient is currently taking
- Submit a copy of the most recent tax return along with a recent paycheck stub
- Make sure that you can provide appropriate documentation such as your patient's Social Security number and the name, address and phone number of the treating physician(s)
- Get the name of the specific case worker who will be reviewing your file

Don't give up!

Be aware that many disability applications, up to 60% of all filed, are denied the first time. Do not give up! You have the right to appeal this denial and can do so very effectively with the proper medical support; physician's notes which indicate a decline in medical condition, the onset of medication side effects, etc. Do not file a new application after a denial; instead appeal the original decision and request that the record be reviewed again. SSDI benefits can be paid retroactively up to a year from the date of official disability. For more on the application process, you may call (800) 772-1213 or visit www.ssa.gov. Once a

person is approved for SSDI or SSI they are able to access many additional resources, such as Medicare and Medicaid. PAF can assist you with this process.

Upon approval for benefits the Social Security Administration will issue a notice of award letter which advises you of their determination. This letter also contains two important terms: *deemed* and *entitled*.

- Deemed: the date that the patient's disability was officially recognized
- Entitled: the date on which the patient can actually begin to access the benefits

Distinction between individual and group policies

Many working adults are enrolled in disability and/or income replacement programs designed to protect their income in the event a disease or medical condition prevents them from engaging in gainful employment. Disability insurance can be obtained through an employer group program or purchased as an individual policy.

Disability insurance is intended to replace income lost due to a medical disability. This coverage may be purchased by individuals on their own "individual policy," or provided as a benefit by employers at no or low cost to employees under a "group policy." Income replacement benefits paid under a group policy are taxable. Benefits paid under an individual policy are not taxable, under the rationale that the policy premiums were totally paid for with after-tax dollars. Adequate income protection should include both a Short Term Disability (STD) and a Long Term Disability (LTD) policy. The STD policy should match the length of the LTD waiting period to ensure there is no lapse in coverage.

Every plan is different. Policy language governs. Read your contract.

Short Term Disability (STD): Group Plans

A typical group policy will pay short term disability benefits for 90-180 days. Sometimes these benefits are funded and administered by an insurer and sometimes funded by the employer and administered by

a third party administrator. The employer is usually very involved with the short term disability claim.

The plan usually will pay 60-100% of pre-disability income, depending on the policy. A cap on benefits is common - for example, a plan may pay 60% of salary up to a maximum salary of \$50,000.00 per year, or may declare a maximum benefit of \$500.00 per week. Certain conditions may be excluded from coverage, or coverage may be limited - for example, a disability that is the result of a pre-existing condition may not be covered until the employee has been covered by the plan for 12-24 months. Disability resulting from elective surgery is a common exclusion.

STD plans are usually more lenient than LTD plans in the type of medical documentation that needs to be submitted to support the claim, since the length of the claim is limited to 90-180 days. **It is almost always necessary for the employee to be under the care of a doctor who will provide satisfactory evidence of disability.** Policy language usually states that an employee may receive STD benefits if medically unable to perform his or her usual job.

Income from other sources usually offsets STD benefits - for example, workers' compensation wage loss benefits. Since workers' compensation pays 66% of pre-disability earnings, no STD benefits may be payable.

Individual Plans

Short term disability policies are not typically purchased on an individual basis. Individuals instead purchase long term disability insurance through an insurance company and the individual deals directly with the insurance company.

Long Term Disability (LTD): Group Plans

Large employers may self-insure and self-administer these plans, but it is much more common for an insurer to be the sole administrator of the claim, and for the requirements for proof of disability to be more stringent. For this reason, it is not unusual for an employee to receive STD benefits for the maximum period and then be abruptly denied LTD benefits. Patients must apply for their LTD benefits. STD benefits do not automatically roll-over into LTD benefits.

Most group LTD plans pay 60-80% of pre-disability earnings for a specific period of years or until age 65. **In order to qualify for benefits detailed medical information must be provided to the LTD carrier as the onset of the claim and periodically throughout the life of the claim is requested. Failure to do so results in denial or termination benefits.**

Usually there is a 60-180 day elimination or waiting period following the onset of disability to qualify for benefits. STD policies are usually written to provide benefits during the waiting period of an LTD policy. It is a good idea to have both an STD and LTD policy. Check the policies to ensure that when the STD plan benefits end that the LTD benefits would begin.

Certain conditions may be excluded or limited as discussed previously in the STD section. Often the policy will limit coverage for so-called “mental-nervous” conditions to a maximum of 24 months. Policy language governs and there is much variation from plan to plan.

Most policies have two definitions of disability - **“Own Occupation”** and **“Any Occupation.”** During the **“Own Occupation”** period, benefits are payable if the employee is unable to perform his or her regular job or a similar job. The Own Occupation period is at the beginning of the claim and is usually two years in length. After that, benefits are payable only if the employee is unable to perform any operation.

During the **“Any Occupation” period**, benefits are only payable if an employee is unable to perform any occupation for which he or she is or becomes reasonably fitted for by education, training and/or experience. Some policies state that if the employee is unable to perform work that pays at least 60-80% of pre-disability earnings, the person will be considered disabled, while others do not take earning potential into account. Income from other sources offsets LTD benefits. For this reason, most LTD carriers require claimants to file for **Social Security Disability Income (SSDI)** as soon as possible. Often the LTD carrier will pay attorney’s fees for the employee who is represented by an attorney at the hearing level.

Some LTD carriers assign rehabilitation professionals to try to help the employee transition back to work. Failure to cooperate with rehabilitation usually results in termination of benefits. Some carriers will

continue to pay full or partial LTD benefits for a specific period of time while the employee is returning to work.

Individual Long Term Disability Policies

Individual LTD policies are available from insurance carriers and can be tailored to the individual's needs. The benefits payable are generally a percentage of pre-disability earnings as evidenced by income tax returns. Premiums and benefit coverage vary greatly, depending on the age, health and usual occupation of the individual. The same general principles are applied for the policies as outlined above.

Appeals

It is important to consult the plan summary or policy to determine how to appeal a denied claim and to file the appeal in a timely manner. Most policies do make allowances for late appeals if an individual is incapacitated or is otherwise unable to file an appeal.

State Sponsored Disability Programs

There are some states that offer state sponsored disability income protection for state residents. These programs are state-mandated and funded through employee payroll deductions. They provide short-term wage-replacement benefits to eligible workers who experience a loss in wages when they are unable to work for a non-work related illness, injury or medically disabling condition. Residents of states that offer these programs should contact their State Department of Labor or Employment for more information.

Subsequent Healthcare Entitlements for the Disabled

In most states individuals who qualify for SSI will also become eligible for Medicaid coverage. For patients who receive SSDI approval they will begin receiving monthly payments only after five full months of disability and will be entitled to Medicare coverage 24 months after the entitlement date, which is the date that a person becomes eligible for payments. Please recognize that it actually takes 29 months from the disablement date until you are eligible for Medicare coverage, not 24 months, which is a common point of confusion for recipients.

For those facing serious illnesses which result in dramatic lifestyle changes and emotional adjustments, these program guidelines may seem overwhelming. Once a young patient receives approval for SSI or SSDI they become eligible to receive numerous healthcare, rehabilitation and educational support services. These services are provided under the Children with Special Healthcare Needs provision of the Social Security Act. These programs are usually managed by state health agencies.

States call these services by many different names, including Children's Special Health Services, Children's Medical Services and the Handicapped Children's Program. Patient Advocate Foundation can provide direct assistance with accessing these additional benefits. Their case management division offers a host of services including assistance with Social Security disability denials, debt crisis intervention, and access to care for the uninsured and underserved patient populations and medical claims reconciliation.

Chapter 4

Insurance...What Are My Options??

Upon graduation of high school, young adults have the world ahead of them with a host of decisions and choices to make. When a young patient is diagnosed with a progressive illness such as cancer, so many choices are taken away. It can feel as though the future has now been decided for them and they have no choices available to them. A student continuing their education at a college level may find it necessary to withdraw from classes in order to return home to have support during treatment for their illness. Often an area of immediate concern is health care coverage. If formerly covered under a parent's insurance plan, a newly diagnosed patient may no longer qualify for coverage under the definition of the plan because of loss of dependent status under the plan rules (i.e.: the patient is no longer a full time student). If covered under a student plan through the college or university, again the eligibility requirement may not be met. The immediate obstacle faced by the patient is maintaining or securing health coverage for needed medical treatment. The challenge for the young adult survivor, long term, is maintaining health coverage for any future needs. There are protections and resources available to patients and education will empower the patient and help them avoid problems that can disrupt much needed medical care.

A student, covered by a parent's plan, is eligible to elect coverage under COBRA should they lose dependent status as defined by the plan language. Under COBRA, the qualifying beneficiary and the qualifying event determines the length of time COBRA coverage is available. Loss of dependent status under plan provisions provides that COBRA benefits are obtainable for a period of 36 months. The premium for COBRA coverage is more expensive as the employer no longer contributes their portion to the plan. Therefore, the patient may have to pay up to 102% (100% of the premium cost and a 2% administration fee) for the premium. Although this may seem to be an outrageous amount to pay, the cost of treatment would far exceed the cost of a COBRA premium.

Some states have health insurance premium payment benefits under their Medicaid program. If an individual is eligible for coverage under

a COBRA plan, the state may provide benefits in the form of premium payments and allow the individual to maintain current coverage rather than be covered by Medicaid benefits. To find out if your state offers this benefit you can contact your local Medicaid office.

Consolidated Omnibus Budget Reconciliation Act (COBRA)

This federal law provides that certain employers with 20 or more full-time employees or equivalent in the previous 12 months are required to offer continuation of coverage under COBRA to qualified beneficiaries. A qualified beneficiary is any individual covered by the plan the day before the qualifying event. Each beneficiary can elect COBRA independently. To learn more about your rights under COBRA you may visit, <http://www.dol.gov/dol/pwba>.

Health Insurance Portability and Accountability Act (HIPAA)

Provides insurance protections for beneficiaries covered by group health plans.

- Limits exclusions for preexisting conditions
- Prohibits discrimination against employees and dependents based on their health status
- Guarantees renewability and availability of health coverage to certain employees and individuals

In order for protection under HIPAA there cannot be a lapse or break in coverage of more than 63 days.

Once a member is no longer covered by a plan they will be issued a certificate of credible coverage to a new insurer. To learn more about your protections under HIPAA, visit <http://www.dol.gov/topic/health-plans/portability.htm>.

Family Medical Leave Act (FMLA)

FMLA entitles eligible employees to take up to 12 weeks of unpaid, job-protected leave in a 12-month period for specified family and medical reasons. The employer may elect to use the calendar year, a fixed 12-month leave or fiscal year, or a 12-month period prior to or

after the commencement of leave as the 12-month period. For more information on this Federal Law visit the Department of Labor website at www.dol.gov.

FMLA applies to all:

- Public agencies, including state, local and federal employers, local education agencies (schools)
- Private-sector employers who employed 50 or more employees in 20 or more workweeks in the current or proceeding calendar

To be eligible for FMLA benefits, an employee must:

- work for a covered employer
- have worked for the employer for a total of 12 months
- have worked at least 1,250 hours over the previous 12 months
- work at a location in the United States or in any territory or possession of the United States where at least 50 employees are employed by the employer within 75 miles

A covered employer must grant an eligible employee up to a total of 12 work weeks of **unpaid** leave during any 12-month period for one or more of the following reasons:

- For the birth and care of the newborn child of the employee
- For placement with the employee of a son or daughter through adoption or foster care
- To care for an immediate family member (spouse, child, or parent) with a serious health condition
- To take medical leave when the employee is unable to work because of a serious health condition

Under some circumstances, employees may take FMLA leave intermittently - which means taking leave in blocks of time, or by reducing their normal weekly or daily work schedule. Also subject to certain

conditions, employees or employers may choose to use accrued **paid** leave (such as sick or vacation leave) to cover some or all of the FMLA leave.

The employer is responsible for designating if an employee's use of paid leave counts as FMLA based on information from the employee.

A covered employer is required to maintain group health insurance coverage for an employee on FMLA leave whenever such insurance was provided before the leave was taken and on the same terms as if the employee had continued to work. If applicable, arrangements will need to be made for employees to pay their share of health insurance premiums while on leave.

Upon return from FMLA leave, an employee must be restored to the employee's original job, or to an equivalent job with equivalent pay, benefits and other terms and conditions of employment. Employees seeking to use FMLA leave are required to provide 30-day advance notice of the need to take FMLA leave when the need is foreseeable and such notice is practicable.

Employers may also require employees to provide:

- Medical certification supporting the need for leave due to a serious health complication affecting the employee or an immediate family member
- Second or third medical opinions (at the employer's expense) and periodic recertification
- Periodic reports during FMLA leave regarding the employee's status and intent to return to work

When intermittent leave is needed to care for an immediate family member or the employee's own illness, and is for planned medical treatment, the employee must try to schedule treatment so as not to unduly disrupt the employer's operation. Covered employers must post a notice approved by the Secretary of Labor explaining rights.

It is unlawful for any employer to interfere with, restrain or deny the exercise of any right provided by FMLA. It is also unlawful for any

employer to discharge or discriminate against any individual for opposing any practice, or because of involvement in any proceeding, relating to FMLA.

Could Medicare be an option even though I am younger than 65?

Medicare is a federal program which helps pay healthcare costs for people age 65 and older and for certain people with long-term disabilities that are under age 65.

It is important to note that Medicare could be an option for young adults who have received Social Security Disability Income (SSDI) for a period of 24 consecutive months.

Could my young patient qualify for Medicaid?

Medicaid is a federally funded, state regulated program designed to provide healthcare coverage for children, the elderly, disabled and pregnant women. Information about coverage is available at your local health department, Social Service agency or State Medicaid office. The social worker at your child's hospital may also be available to assist you in completing the application. Be sure to ask for assistance if it is not initially offered. You may also visit the website, <http://www.cms.hhs.gov/medicaid/statemap.asp> and select your state of residence to view eligibility criteria.

It is important to note, that if your young patient is approved for Supplemental Security Income (SSI), they would be eligible for Medicaid.

We are a military family. Are our coverage options for our young patient different?

Tricare (Civilian Health and Medical Program of the Uniformed Services) would be the primary option for you as this plan is exclusively for active duty and retirees and their immediate dependent and qualified survivors. Additionally, depending on your location, treatment may be available to you directly through your local military treatment facility (MTF), their families, and survivors.

We live on an Indian reservation. What medical assistance are we entitled to?

The Department of Health and Human Services Indian Health Service, a federal health program for American Indians and Alaska Natives, provides medical assistance to eligible American Indians at Indian Health Service (IHS) facilities, and selected healthcare services provided at non-IHS facilities. To receive IHS benefits, you would need to go to your IHS facility's registration office in person and present proof of your enrollment as a member of a federally recognized tribe. Please visit www.ihs.gov to learn more.

I've read all of the options, but we either don't qualify financially or medically as my child now has a "pre-existing" condition. Now what?

If your young patient is in need of medical care, but you do not have insurance, don't panic. There are facilities that offer charity care and/or financial assistance programs. You will need to find a hospital/provider that offers such assistance. When calling a hospital/provider you will need to speak with a social worker, patient advocate or financial counselor and ask for an application for charity care/financial assistance. Each facility will have their own specific eligibility requirements for charity care, which are typically based on income/assets as well as household size to determine the level of assistance the facility will be able to offer. Some may offer 100% charity care and others may use a sliding scale fee based on your income.

When applying for charity care, keep in mind that any hospital charges will be covered, but there will be providers that bill separately. You will need to make separate arrangements with these providers. Occasionally, if the hospital is doing a charity write-off for your young patient's care, the physicians will follow suit. If charity care is not available, discuss making reasonable payment arrangements with the provider.

Another option would be to access your state's Hill-Burton facilities, if available. These facilities provide limited care to uninsured patients. To locate a Hill-Burton facility in your area, call 1-800-638-0742 or visit their website at www.hrsa.gov.

The State Children's Health Insurance Program (SCHIP) is a federal program that requires states to provide health insurance to children

from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. The program provides coverage for prescription drugs, vision, hearing and mental health services and is available in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about this program, or you can get more information at www.cms.gov/schip on the Internet or by calling 1-877-543-7669.

Some states have their own health insurance programs for low-income uninsured individuals and others have what is called “risk-pool” insurance, which is an option for high risk individuals. These state programs serve people who have pre-existing health conditions, and are often denied or have difficulty obtaining other coverage. To find out if your state participates in any of these plans, you will need to contact your state’s Insurance Commissioner’s Office, or visit www.naic.org.

Our family has health insurance, but it hardly covers anything. Any suggestions?

You may apply for Medicaid in this instance as well. Medicaid can become a secondary insurance. The local Medicaid office will need verification of your primary insurance coverage.

As well, if your young patient is uninsured for pharmaceutical coverage or the benefit for pharmaceutical coverage you have is minimal, there are co-payment assistance programs available should your young patient financially and/or medically qualify. This will be discussed further in Chapter 7: Preparing for the Possibility of Financial Burdens.

What if my child’s healthcare needs exceed the lifetime maximum of our plan and care is still warranted?

You should apply for Medicaid in this instance as well. You may be asked to provide proof of the exhaustion of the LTM (Lifetime Maximum) typically done through a letter from the insurance company. Another option that some parents of critically ill children may consider is changing employment. With a new employer health plan you will start over on your lifetime maximum.

What happens if my young adult is no longer eligible for my insurance coverage due to their age and/or is not a full-time student?

If your child is over the age of 18 (or as otherwise specified in the policy) and/or has graduated from college, he or she may be entitled to COBRA benefits. COBRA coverage would allow your child to remain on your plan as a dependant for up to a maximum of 36 months. Typically, an insurance policy places limits on college students. However, any policy will clearly outline its limits and/or exclusions. In most circumstances, insurance policies will cover any dependant children up to age 24 or 25 as long as documented proof is given that he/she is a full-time student in college. Once COBRA benefits have exhausted, the best option would be for your child to secure full-time employment with an employer that offers group health coverage. As long as there is not a 63 day or greater lapse in coverage, your child can enroll into a new employer policy without being subject to any pre-existing clauses, regardless of previous health conditions. If there is a 63 day or greater lapse in coverage you will still be eligible for employer sponsored coverage if offered however a 12 month pre-existing condition clause may be applied. This means that a beneficiary can access all healthcare benefits offered through the plan except those treatments and/or therapies relative to a pre-existing condition for 12 months.

Another coverage option to consider for your young adult is the purchase of an individual insurance plan. Although, if your state does not offer guarantee issue plans an applicant can be denied coverage due to any pre-existing conditions. The insurance carrier can also attach a rider to the policy excluding coverage for any pre-existing conditions for the life of the policy.

In summary, it is important to note that when signing up for health insurance it is no different than when signing up for and enrolling into an auto or homeowner's policies. You are entering into a contract with an insurance carrier. Regardless of whom your insurance carrier is or what type of insurance you have, you are subject to the terms of the policy. It is critical as a caregiver of a young patient to understand the way your policy works so you can maximize your benefits and receive the best coverage allowed under your plan. It is imperative that you read your plan carefully. If you have any questions regarding any part of your policy, refer to the phone number provided on your insurance card.

Chapter 5

Access to Care Issues for the Pediatric and Young Adult Populations

There are a lot of things going through a caregiver's mind when their young patient is diagnosed with a chronic or life-threatening condition. Does my loved one have access to the best care? Do we have access to a second opinion? What do we do, as we have no insurance or means to pay for the care? This is just a sampling of the many things possibly going through the mind of a caregiver of a young patient as they prepare to face the long journey of caring for a sick child or young adult. This section is designed to answer some of the above questions so that caregivers can become more knowledgeable and better prepared at the time of diagnosis.

How can I get access to the best medical care possible?

What do you do when your young patient is diagnosed with a chronic or debilitating condition? Obviously, you want the BEST care possible for your loved one and will do whatever it takes to attain that. You may have questions or concerns regarding the doctor's medical decisions and/or proposed route of treatment. This is a common issue experienced by parents and caregivers when learning their young patient is ill and initially faced with several options and opinions that have been set before them.

It is important to remember that your insurance plan will frequently outline coverage levels for different medical facilities, providers, treatments and/or therapies. It is important that you review your insurance coverage upon initial diagnosis to fully understand what provisions it offers for specialized pediatric and young adult care. For example, if you live in an area that has a designated specialist/facility that treats your loved one's condition and is covered by your insurer and you elect to go to another specialist/facility that is equally equipped to treat your loved one but is not designated as an approved facility by your insurer then you may need to be prepared to pay higher out of network charges that may occur as a result of choosing another specialist or facility. There are certain criteria that must be taken into account when faced with the above scenario. First, does your insurance

plan offer coverage in that other area of service? Do you need a referral? One must be aware of the policy language and its interpretation of the charges and costs related to going to another provider or facility. There are almost always other charges and costs that may need to be taken into consideration when making choices as to where to take your young patient for treatment and what physicians to see.

Most importantly, you need to understand fully your loved one's diagnosis and seek medical care from a provider who routinely cares for patients suffering from that illness. Young adult patients may be particularly vulnerable as many of the cancers diagnosed in this population are actually pediatric varieties and yet the young adult patients often receive medical advice and treatment from a physician who is not specialized in treating pediatric oncology patients. Should the diagnosis rendered be rare or unusual, you may want to seek additional education about the disease and physicians who treat them from the National Cancer Institute. Clinical Trials may also be a viable option for your young patient and can also be researched through the National Cancer Institute by visiting www.cancer.gov.

Am I entitled to a second opinion?

Most definitely, all newly diagnosed patients are entitled to a second opinion and most insurers routinely provide reimbursement for them as well. This is particularly true if you have a valid concern regarding the medical advice that your loved one is receiving. For example, if a young patient is receiving treatment from a provider that doesn't specialize in that condition, depending on the insurance policy language, most will be entitled to a second opinion by a more qualified provider. It is always imperative to check with the insurance company initially to make sure that there will not be any potential coverage issues when seeking a second opinion. Also, if a caregiver of a young patient is looking for a provider that sees more cases of a particular disease, it might be necessary to consult with them and make sure that the young patient is receiving the right treatment for their condition.

Are there Out-of-Network (OON) benefits available through the medical plan, and what is the percentage of coverage available?

One must first become educated as to what type of insurance plan they have. If the patient is a member of a Preferred Provider Option (PPO) or is a member of a Point of Service Plan (POS), there are OON

options available, but they do not pay the same if treatment or care was given in-network. If the patient is a member of a Health Maintenance Organization (HMO), there are frequently no OON benefits and one would be forced to incur 100% of the expenses of any care received OON. It is extremely important to note that OON expenses can be extremely costly as the OON provider does not have a contract with the insurance company. The OON provider can accept payment from the insurer, but doesn't have a contractual obligation to write off any of the balance resulting in the patient being balance billed for the entire amount. This ultimately becomes an additional burden financially to a family already battling a chronic condition.

My child is uninsured; access to care is a real issue. Are there any additional options?

Did you know that your child may be eligible for free or low-cost health insurance? All states offer a health insurance program for infants, children and teens. The insurance is available to children in working families, including families that include individuals with a variety of immigration status. For little or no cost, this insurance pays for:

- doctor visits
- prescription medicines
- hospitalizations

Kids that do not currently have health insurance are likely to be eligible, even if you are working. Each state has different eligibility rules, but in most states, uninsured children 18 years old and younger, whose families earn up to \$34,100 a year (for a family of four), are eligible.

To learn more, a toll free call can be made to 1-877-KIDS-NOW for more information or visit www.insurekidsnow.gov

Is there a program within my State that my child can have access to insurance?

As part of the Balanced Budget Act of 1997, Congress created Title XXI, the State Children's Health Insurance Program (SCHIP), to address the growing problem of children without health insurance.

SCHIP was designed as a Federal/State partnership, similar to Medicaid, with the goal of expanding health insurance to children whose families earn too much money to be eligible for Medicaid, but not enough money to purchase private insurance. Each state determines the design of its program, eligibility groups, benefit packages, payment levels for coverage, and administrative and operating procedures.

SCHIP is designed to provide coverage to “targeted low-income children.” A “targeted low-income child” is one who resides in a family with income below 200% of the Federal Poverty Level (FPL) or whose family has an income 50% higher than the state’s Medicaid eligibility threshold. Some states have expanded SCHIP eligibility beyond the 200% FPL limit, and others are covering entire families and not just children. Please visit www.cms.gov/schip to learn more.

What about clinical trials?

Clinical Trials are research studies designed to find better ways to treat a disease. Clinical trials often compare the most accepted treatment, which is considered “standard treatment” with a new emerging treatment that doctor’s hope will be better. Each study has rules about who can and cannot participate. For example, the patient’s age, sex, or stage of disease could be a qualifying or disqualifying factor. You would need to discuss this option with your young patient’s medical professional to explore any opportunities that he/she may medically qualify for.

As a caregiver to a young patient, is it important to make sure they will continue to have the long-term care and follow-up required. It is crucial to maintain a copy of the medical records and also to maintain consistent insurance coverage. One must always keep in mind that once diagnosed with a chronic and/or debilitating condition; it becomes more and more difficult to obtain insurance. Getting a good policy and maintaining one is the key to good preventative care!

Chapter 6

The Importance of Keeping Reliable Medical Records

In today's healthcare environment it is so important to keep up-to-date, reliable medical records from birth through adulthood. When children become independent and in control of their own healthcare as young adults, this information will enable them to make educated and informed decisions should a health situation arise later in life. This comprehensive information will also enable medical professionals in the future to have the documents needed to provide a thorough treatment regimen based on any individual's prior history, parental health history, allergies and/or complications previously experienced as a result of medical interventions. Personal health records are helpful in maintaining up to date treatment protocols, prescription information and diagnosis history. Check with your health providers to confirm if they offer electronic health records and if so, will they update your record at each healthcare transaction. The electronic health records eliminate paper, maintain current information, reduce medical errors and assist the patient with conforming to treatment protocols. Many health plans and employers maintain electronic health records on each beneficiary and allow the beneficiary access to view and/or download the health records electronically. This process allows for maximum portability.

If your young patient has been diagnosed with cancer for instance, the likelihood of survival and permanent remission is at an all time high according to today's statistics. However, if a childhood cancer survivor should encounter any health issues as a young adult, the treating physician is going to want to know past clinical history. For example, what pharmaceutical products were administered as part of their chemotherapy regimen? What specific treatments were prescribed? What maintenance drugs had they been taking? This information is ever so valuable to the medical professional as they attempt to adequately diagnose and/or rule out late stage medical complications resulting from care rendered many years prior to the onset of new symptoms. This ultimately results in less time being wasted recalling facts and focuses immediate attention to the situation at hand – becoming well.

For caregivers of young patients with a chronic, life-threatening illness and/or disability, we recommend that a record book be developed to contain information about the patient's medical care in an organized and easy to find manner. Below are a few important steps to get organized.

It would be recommended that a large binder, dividers, a hole puncher and notebook paper be bought to put together a cumulative listing to contain the below sections:

- **Profile:** This section should give a concise overview of your young patient. Include his/her likes, dislikes, opinions, strengths/weaknesses, etc.
- **History:** This section should include a family tree. Include any significant illness that an immediate family member had, any pregnancy complications, developmental history and any significant events your young patient has experienced.
- **Concerns:** In this section you should record all of the past and present concerns you have in regards to your young patient. It would be important to keep a record of the concerns that you mentioned to any professional and what their position was.
- **Medical:** Use this section to file all medical correspondence received.
- **Diagnostic or treatment reports:** Use this section to file all information related to medications and treatment regimens.
- **Psychological/social:** Use this section to file all information related to the psychological, emotional and social behaviors of your young patient
- **Educational:** This section will include all information related to your young patient's performance in school, if applicable. For example, you would want to include teacher reports, nurse reports, report cards and Individualized Education Programs (IEP).

It is important to stress that medical records are the key to providing legal proof of care. The medical professional has a legal obligation to

maintain medical records regarding your young patient, but sometimes that does not translate into orderly or centralized record keeping. This is why it is important that caregivers take an active role in regards to documenting, locating, organizing and housing the medical records of their young patient. This ultimately is a big step in the right direction in seeking fair and proper treatment when medical conditions arise presently, or most importantly, arise later in life when the need for reliable and updated medical information is imminent.

Chapter 7

Preparing for the Possibility of Financial Issues

When a young patient becomes ill, families are faced with so many uncertainties in regards to their future. Without an understanding of what resources may be available, the thought of the long road ahead can oftentimes be unbearable.

Families can deplete an entire life's savings in a short amount of time when faced with a young patient's life threatening illness. What will you do? How will you keep your home? How will you buy food, pay your utilities and other bills? Will you be left with no income for a period of time? How can you access the benefits that your young patient might be entitled to? Are you uninsured and do not know how you are going to even afford your child's treatment?

This chapter will help you prepare for the financial demands that your young patient's illness will create. We have also provided a comprehensive Resource Appendix at the end of this publication which outlines numerous resources for patients.

Apply Early for Disability Benefits on behalf of your young patient

Please refer to Chapter 3, The Ins and Outs of the Disability Process, for comprehensive information regarding available disability benefits.

Applying for Financial Assistance

When applying for financial assistance, please recognize that many organizations have specific criteria, which must be met in order to qualify for financial assistance and that some organizations may have assistance in an area that you do not immediately need. Be creative however in your approach to utilizing this assistance. For example, you may need financial assistance to pay your health insurance premium and an organization will provide assistance for your utility bill. Take advantage of the financial assistance for the utility bill and reallocate your money to pay your health insurance premium, if the program permits reallocation.

In general, most organizations will not provide financial assistance for secured debt, such as a mortgage or an automobile. Your best option for this type of debt would be to work direct with the creditor and ask for alternative payment arrangements for the loan, such as refinancing, deferring payments, or paying only the interest due. If you cannot get the creditor to work with you, you may consider selling the item. A home mortgage is usually at risk of foreclosure after three months of delinquency. Typically, mortgage lenders are more cooperative when they are approached before a mortgage reaches foreclosure.

Strategies for resolving your Debt Resulting from Illness

Do you own your home? Or have a mortgage?

Call the bank or mortgage holder early and try to work out payment arrangements. Consider selling, taking a second mortgage, taking a reverse mortgage or establishing an equity line of credit.

Do you rent?

Apply for Section 8 housing (a voucher/certificate that helps you pay your rent), Public Housing, or consider moving to a residence with less rent.

Do you need help with your utilities?

Check to see if your state has a Low Income Heating Energy Assistance Program (LIHEAP). Ask the utility company if they have any charity programs available. Call the Department of Social Services in your area to see if they have any information about a Community Action Agency, an organization who can usually assist when a shutoff or eviction notice is given. Ask your doctor to write a letter of medical necessity to the utility company, as they may be more willing to work with you relative to your condition. Lastly, you may contact the State Utilities Commissioner to request their review of a compassionate appeal. For more information on the LIHEAP program, call **1-202-783-5594**.

Your electric company may also have a fuel fund. This is the fund that your neighbors contribute to. Look on your electric bill for the number in your area.

HearShare is administered by the Salvation Army and provides emergency energy assistance on a year-round basis. Funds are used for natural gas, oil, propane, wood, electricity and emergency furnace repairs. For more information, call **1-800-842-7279**.

Do you have outstanding medical bills?

Ask your provider of care to allow you to apply for Charity Care or Indigent Care. If you do not qualify, ask to make payment arrangements that you can afford. If you cannot establish reasonable payment arrangements, contact the Consumer Credit Counseling Services for assistance. Call (800) 493-2222 or (800) 388-2227 to locate an office near you.

If you have mounting medical bills, do not allow them to go into collections. Contact the billing office of the provider that you owe money, and offer the most minimal payment you are realistically able to make. When negotiating a payment, keep in mind that you are making a binding agreement. You cannot default on your payments, so make sure the monthly amount is feasible for you and your family. You must also realize, when negotiating payment arrangements, that the facility/provider is a business and must be able to collect a reasonable amount. If you are able to make a lump sum payment, that facility may be willing to write a portion of the balance off.

Don't forget your medical bills while filing your taxes. Medical expenses are tax deductible. Keep all receipts and records of payment. Examples of tax deductible expenses include mileage for trips to and from medical appointments, out-of-pocket costs for treatment, prescription drugs and/or equipment and the cost of meals during medical visits (<http://usovinfo.about.com/library/weekly/aa061800b.htm>).

Do you have credit card debt?

If you find yourself unable to pay your credit card bill(s), contact the creditor to make payment arrangements that involve the most minimal payment you can afford. Be specific in the amount that you are able to afford. If you are unable to establish payment arrangements, contact the Consumer Credit Counseling Services for assistance. You can always give them more money each month, but want to make sure you are at least paying the minimal amount due. Charitable organizations are not likely to assist you with making these payments.

It might be in your best interest to contact a credit counseling center for debt consolidation. They are able to negotiate lower interest rates and payment arrangements. Only contact those companies that are non-profit.

Do you have life insurance policies with equity?

Consider using an organization that loans money against whole-life policies, which reduces the payout amount at the time of death. Term-life policies cannot be used for this purpose. One organization, Life-Wise, can be reached at (800) 219-7385.

Do you need medication? Are you are uninsured or without prescription samples?

Check with your state to see if they operate a prescription drug program. Apply for the Medicine Program or have your doctor apply for the Indigent Drug Program through the drug manufacturer. Call the Pharmaceutical Manufacturers' Association (PHRMA) at (800) 762-4636 and ask for the patient helpline to get further information regarding this program.

Managed RX is a program that accepts most major medical insurance as full payment for prescribed medications. If your prescription benefits pay a minimum of 70%, Managed RX accepts that as full payment for the medication and waives the co-pay. Medications are shipped at no cost to you. Call **1-800-799-8765** for an application.

What is the Patient Advocate Foundation's Co-Pay Relief Program?

PAF's Co-Pay Relief (CPR), A Patient Assistance Program provides direct financial assistance for pharmaceutical co-payments to insured patients who meet certain qualifications. Once approved for the program and depending on the level of help needed, payments are made:

- To the doctor
- To the pharmacy
- To the patient directly

Who is eligible and how to apply?

This program offers personal service to all patients through the use of program call counselors. These counselors screen for eligibility by collecting financial and medical information from everyone who calls to apply for the program. Once eligibility has been determined, a comprehensive application will be completed and processed. Patients will be assigned their own call counselor who will be available to answer any questions during the process. For more information, please call 1-866-512-3861.

What type of assistance can your community offer?

Civic, religious, and fraternal organizations also might offer financial aid or services to assist the patient and family. Groups such as the Salvation Army, United Way, Lutheran Social Services, Jewish Social Services and the Associated Catholic Charities can be found in the yellow pages under “Social Service Organizations.” Also, churches and synagogues sometimes provide financial help to their members; however, you do not have to be a member to qualify for assistance with many religious organizations.

If financial aid is not available, these and other organizations may be able to provide transportation to and from the treatment centers, babysitting services and special equipment and dressings for home care. Services are sometimes available through organizations that are specific to your diagnosis.

Local charities are often willing to provide financial assistance for such needs as clothing, utilities, rent, furniture and other necessities while funding is available. Check your local listings for charitable organizations in your area.

Could you use help with getting food?

If you are having a difficult time affording an adequate amount of food, there are places to turn. Contact your local social services office to apply for food stamps. Food stamps will allow you to purchase food at the grocery store. Those who are eligible for the food stamp program will receive a plastic card that is swiped just like a debit or credit card. Almost every community in America has a food bank program. Check your phone book for a list of local food banks.

Fundraising...another option

- Start in your hometown. Check with your local library and any local foundations or agencies that pertain to your specific kind of medical needs for fundraising how-to information.
- Check with your local hospital's Department of Social Services for fundraising information and opportunities.
- Local retailers have also been known to help people who want to hold raffles for cars or televisions and to support placement of the containers with pictures next to counters suggesting donations. You should contact the human resources department or administrative offices of these organizations to see if they participate. Your local Retailers Association may also be a good place to contact a group of local retailers to explain your needs and ask for support.
- Your local churches area also a good place to start as they already have the support of the community.
- Who helps you implement your fundraising? Friends and family should be encouraged to assist as well as local fraternities and charities that often help with marathons and other events involved with fundraising.
- Get the media involved! Human interest stories are always needed by the media and nothing completes one better than a community pulling together to help people in crisis. Make sure that a newspaper or a reporter is 'in the know' about any of your fundraising events and has your information regarding your financial needs as to your struggle to obtain medical care.

What events work for fundraising? The answer is simple....Any that you can get your community involved in supporting. Get local entertainers to donate their services and have local celebrities such as the mayor, state legislators, Senators, House of Representative members, local heroes, and community leaders to speak. Stage at a "special location," one that everyone loves in your area. Invite the media. Provide fact sheets to them in advance about your case. Get the TV

stations to bring their cameras and put the interviews on their nightly news! Then send lots of thank you letters to the editors of papers that covered your event and to radio and TV stations management.

Chapter 8

Respite Care...Take Advantage!

Respite care programs for the chronically ill are designed to assist caregivers in meeting the needs of medically complex young patients. Every caregiver needs to take a break from the daily responsibilities of providing care to rest and rejuvenate. Caring for a chronically ill young patient can drain you physically and emotionally. You can not effectively care for a loved one for an extended period of time without a break to care for yourself!

Respite care can be provided in the home or in specially designed facilities. A clinical coordinator will usually meet with you to assess the special needs your young patient may have and assign the appropriate caregivers to work with your family to meet you and your physician's goals for your family member.

Families, who provide at-home care for a family member with a chronic illness may occasionally need short-term help or relief from caregiver responsibilities. Respite care will allow you time off to care for your family and yourself. Care can be provided in a number of ways including 24 hours a day, 7 days a week; intermittent days or evenings; or hourly blocks to provide respite from the constancy of care. The average length of stay is variable, and will be arranged to fit your personal needs. Often, young patients who participate in respite care programs look forward to fun activities and thoroughly enjoy the company of peers. When prescribed and appropriate, they can also benefit from therapeutic support to help them develop skills and function.

The primary goals of respite care are to:

- Support families with chronically ill or technology dependent children
- Provide instruction in using special medical equipment, administering medication and therapy
- Assist with referral to and coordination with physical, occupational and/or speech therapists

- Facilitate coordination of care with case managers, pediatricians, caregivers and others as needed.

Services are generally paid for by Medicaid Waiver programs or by the beneficiary's health insurance plan.

The medical professionals assigned to your young patient are directly related to your patient's individual medical needs and may include: Registered or Licensed Practical Nurses, Respiratory Therapists and Physical and/or Occupational Therapists. Nursing care may include: breathing treatments, ventilator care, wound care, special monitoring of apnea and oximetry; cardiac monitors, special feeding needs, nasal gastric and central line therapies.

Chapter 9

The Early Intervention System....What is it and how can My Child Benefit?

One does not need to describe the difficult emotions that accompany learning that your child has been diagnosed with a chronic or life-threatening illness. In addition to dealing with an initial diagnosis, there are often many other issues that need to be addressed in conjunction with the treatment for the actual diagnosis at hand. As a result, sometimes the child at presentation appears to be developmentally delayed and/or has a potential disability. It is a heart-wrenching experience and caregivers are left in the dark as to where to turn. It is evident that one of the best things we can do for our children is to become informed and educated about services that are available.

Early intervention is a wonderful system designed to ensure that our little ones get their best start in life. A major component of early intervention is that caregivers are partners or team members working together with a variety of professionals. Caregiver participation and informed choices are strongly encouraged as they are an important part of the process as you make decisions for your child.

What is Early Intervention?

Early intervention is a coordinated system of community services for young children who have disabilities or developmental delays, as well as for the families of such children. Through this system, agencies, caregivers and providers work together to provide children services to meet their developmental needs.

Early intervention services are for infants and toddlers from birth through age 2 who are not developing as expected or who have a condition which can delay normal development and includes services to the families of such children. These services are provided to promote a child's development and to assist families in meeting the developmental needs of their child.

Early intervention service providers work in partnership with families to find young children who are eligible for services, to determine what

these children need, and to provide services for which the child's family gives permission. Family involvement is important at every step along the way.

How can I find out if my child can get these services?

If you have a concern about your child, call your state's toll-free number or call the telephone number for the early intervention contact in your area. Each state decides which of its agencies will be the lead agency in charge of early intervention services for infants and toddlers with special needs. In your state, the first contact person may be an early interventionist (an early childhood specialist working with infants and toddlers), someone with the lead agency, or someone in your state's Department of Social Services.

To find out who can help you in your area, contact the person listed on your State Resource Sheet under "Programs for Infants and Toddlers with Disabilities." If you don't have a State Resource Sheet, call the National Information Center for Children and Youth with Disabilities at 1-800-695-0285. Explain that you want to find out about early intervention services for your child and ask for a name in your area. It is important to write down the names and phone numbers of everyone you talk to. Having this information available may be helpful to you later.

Normally, within 2 days after you or someone else makes a referral and you give permission for evaluations to take place, a service coordinator will begin working with you and your family. This person will help you find out if your child is eligible for services. Your service coordinator's role is to assist you during the referral, evaluation and eligibility process. The service coordinator will gather information from you about your child and make arrangements for evaluations. Under Public Law, evaluations and assessments are provided at no cost to families. You would need to check with your local office for specific guidelines.

With your signed permission, your services coordinator arranges for an evaluation to learn about how your child is developing. If your child has already had an evaluation, additional evaluations may not be needed. Your service coordinator will make sure that any procedures used are right for your child and are sensitive to your family's needs and culture.

During the evaluation process, your child will be given a fair chance to show what she or he can do. Your child will be tested by a group of professionals who represent at least two professions or areas of development. Evaluators may include infant educators, speech therapists, physical therapists, occupational therapists, social workers, nurses and/or others. The evaluation will include tests in cognitive development, physical development, and gross or fine motor development, communication, emotional development and adaptive development.

What Early Intervention services are available?

Early intervention services are designed to meet the individual developmental needs of each child and family. Because no two children or families are alike, there are many kinds of early intervention services. All families can receive help from a service coordinator. The evaluation process determines which services are needed for an individual child and family. Services may include:

- Assistive technology devices and services
- Audiology services
- Speech-language pathology services
- Family training, counseling and home visits
- Health services
- Nursing services
- Medical services (for diagnosis or evaluation only)
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological therapy
- Speech instruction
- Transportation and related costs
- Vision services
- Service coordination visits
- Social work services

Ask your service coordinator or social worker about other services that will help your family give your child a good start. Some families receive only a few services. Others receive more. It depends on your child's and family's needs. Remember, no child is ever denied services because of an inability to pay. Usually, services are provided at no cost to the family. You may have to pay for some services,

depending on your state's policies. In some instances some services may be covered by your health insurance, by Medicaid, or by Indian Health Services. Once your maximum visits are depleted, services may be charged a "sliding-scale" fee that is based on what you earn. Every effort is made to provide services to all infants and toddlers who need help, regardless of family income. It is important to note that one has to seek services from an early intervention provider to receive these discounts and not every practitioner participates within the early intervention system.

What happens when my child is too old for Early Intervention?

By the time they leave early intervention, some children have received all the help they need and no longer need special assistance. Others still need some more help. This can be provided by community agencies, private providers or by the early childhood special education system in the public schools.

Your local school system provides early childhood special education for children with disabilities under what is called Part B of the IDEA (Individuals with Disabilities Education Act). IDEA requires that all states and territories provide a public school education to children with disabilities from ages 3 to 21, no matter how severe their disabilities are. In most states, eligible children who will be two years old by September 30th can begin early childhood special education at the start of the school year. Most two year olds move to preschool in September of the year they are eligible. Transitions for some two year olds may be delayed until later in that school year. You decide when your child transitions. Early intervention services continue to be available until the transition occurs or until your child's third birthday. Please remember to check within your specific state for details!

Special education laws guarantee a free appropriate public education for eligible children with disabilities. Eligibility requirements and services are not exactly the same as for early intervention. Not all children who receive early intervention services will be eligible for or need special education. Special education focuses on your child's educational development, delays and needs.

I live in a remote or rural area. How can I receive services?

The goals of early intervention or special education programs and services for young children with special needs are the same for both rural and urban families. However, the ways in which these services are offered may be different. Two groups that may be able to offer information specifically about services for rural families are the American Council on Rural Special Education (ACRES) who can be reached at 1-888-866-3822, www.acres-sped.org and The Rural Institute on Disabilities who can be reached at 1-800-732-0323, www.ruralinstitute.umd.edu.

What about services for Native American families living on reservations?

The lead agency for the state is responsible for seeing that early intervention programs and services are provided to infants and toddlers (age's birth through two years) with special needs in the state. The State Education Agency (SEA) is responsible for seeing that programs and services are provided to preschool children (age's three through five) with special needs. These requirements include Native American infants, toddlers, and children living on reservations. Information on these services is available from the lead agency, from the SEA, or by contacting the office of the tribal leader or the tribal education committee. Local public or Bureau of Indian Affairs (BIA) schools and Indian Health Service offices and clinics are also possible sources of information.

What additional information do families of adopted or foster children with disabilities need about early intervention or special education services?

In general, the process for getting early intervention or special education programs and services for adopted children with special needs is the same as it is for all children with special needs.

An organization that has a nationwide family support network of adoptive families is Adoptive Families of America (AFA). While the main focus of this organization is to provide general help and information to all adoptive families, its bimonthly parent support magazine includes information and resources for families of adopted children who have special needs. Please visit www.adoptivefamilies.com to learn more.

Families who provide foster homes to children who have disabilities or who are at risk of developing disabilities may want to contact the National Foster Parent Association, Inc. (NFPA). This national, non-profit group offers information and support to all foster parents. Members of the group receive a bimonthly newsletter and have access to nearly 500 NFPA resource materials. The NFPA can be reached at 1-800-557-5238 and/or www.nfpainc.org.

Are there any programs and services for military families whose young children have special needs?

One way is through a project known as Specialized Training of Military Parents (STOMP). This organization provides information and help to military families (both in the U.S. and overseas) who have children with special needs.

The STOMP staff is made up of parents of children with special needs who are trained to work with other parents of children with special needs. As spouses of members of the military, the staff understands the unique needs of military families. If needed, you can contact 1-888-5-PARENT and/or visit www.stompproject.org.

Another way to learn more about early intervention and special education programs and services for children in military families stateside is to contact the Community Service Center (also called Family Service Center or Family Resource Center) or the assigned community contact person on your installation.

Cancer and Fertility: A Forgotten Concern for Today's Young Survivors

Today, almost one million Americans younger than 40 years old are cancer survivors. Today nearly 80% of children and teenagers diagnosed with cancer now live at least 5 years, and many of those are cured. This number continues to increase each and every day. With the increase in survivorship overall an important quality of life issue is becoming more important: how can a young adult patient preserve their ability to become a parent after cancer treatment? Thanks to advances in reproductive technologies, there are now ever increasing ways to achieve and preserve parenthood for those surviving cancer.

We hope that the information provided below will help patients and/or caregivers become educated and proactive in regards to infertility issues and will enable them to explore discussions with their health care providers, make informed decisions, and be proactive in regards to available fertility preservation options.

Why are adolescent and young adult survivors particularly hard hit by infertility?

According to the Journal of Philosophy, Science and Law, more than 70% of children and young adults with cancer can be cured. This remarkable statistic is the result of more than 35 years of collaborative laboratory and clinical research in the United States and abroad. As a result, it has been estimated that as many as 1 in 250 adults under the age of 45 will be a long-term survivor of childhood cancer by the end of this decade. Thus, we are currently caring for a unique population of aging cancer survivors. However, this success has come at the price of late and long-term side effects, from both the initial disease and from the cumulative aspects of curative treatment. One of the most devastating of these complications is infertility.

The affects of cancer treatments on the reproductive system for patients under the age of 25 have not been adequately studied and are not well known. Concerns about fertility and becoming a parent down the road seem to be often neglected obviously by the patient due

to his or her age. This is also neglected by caregivers, since overall survivorship is the main concern, not to mention dealing with the devastation learning and accepting that your young patient has been diagnosed with a life-threatening disease. Caregivers are in the midst of making urgent and immediate treatment decisions and potential fertility issues are more likely to be overlooked unless brought up by a medical professional. Unfortunately, young adults typically have the least amount of health insurance in today's society. The result of this statistic puts young adults in a compromising situation in having the least access to financial resources, making access to fertility procedures unattainable for most.

Why are pediatric cancer patients a critical population for fertility issues?

In addition to dealing with all of the clinical issues surrounding them as a young patient, the psychosocial issues differ tremendously from those of adults. While learning to cope with treatment and the side effects experienced, young patients experience emotional distress in regards to a variety of issues such as the interruption of school, etc. Self-esteem issues as to body image i.e.: hair loss, weight gain and simple uncertainty about the future. And, like all young patients, they struggle with concerns about dating and marriage, relationships with friends, becoming independent from parents and assuming responsibility of their own life to include their health care.

With that said research across the board states that long-term survival rates for childhood cancer are at an all time high. These rates support the importance of survivorship issues such as long-term reproductive function in addition to other issues faced by young patients as mentioned above. This population is critical in regards to fertility as it has been learned that options available for fertility preservation for patients who have not gone through puberty, are limited as well as medical professionals serving this population have demonstrated little knowledge of fertility preservation options available to their patients. Fertility is also critical in this population as the issue of fertility preservation within these ages is simply overlooked as parents and caregivers are normally dealing with the immediate decisions that must be made when dealing with the patient's treatment regimen and survivorship outcome.

Are fertility options available for young patients?

Fortunately, fertility options are available for the vast majority of young patients and can be found in the Resource Appendix at the back of this guide. These options are for both male and female and can occur before, during or even after treatment has ceased. However, it is strongly suggested this issue be brought to the attention of the treating physician for discussion and exploration prior to the implementation of a treatment protocol if this is a concern for the patient or caregiver.

What are the long-term effects of damage to the reproductive system?

Some long-term effects genuinely deal with the lack of knowledge about possible infertility at the time of diagnosis which ultimately contributes to feelings of anger, loss and strain on relationships down the road when trying to conceive becomes a priority. This ultimately has negative implications for the overall survivorship of the patient as do all stressors of this nature. The National Cancer Institute does suggest that childhood cancer survivors do experience late effects that can affect future pregnancies as well as certain stem and bone marrow transplants do increase the risk of infertility. However, as noted previously, there are methods used to assist childhood cancer survivors in regards to having children such as freezing the eggs or sperm before treatment in patients who have reached puberty as well as in vitro fertilization treatment.

What should doctors do to help their patients?

Doctors must keep their patients abreast of the current information regarding potential infertility as a late effect and discuss the options that can be used to preserve it. This will keep the patient up to date on advances in regards to their fertility preservation while being able to concentrate on their overall survivorship and not worry needlessly about the future's uncertainty's.

Are fertility preservation treatments covered by insurance?

It is typical for diagnostic tests for infertility to be covered under insurance. However, treatment costs are usually a non-covered benefit under most plans. Therefore, without insurance coverage some patients

have to pay for these treatments out of pocket. This issue represents a major barrier patients can encounter when faced with the possibility of potential infertility as their access may be limited due to severe financial constraints. However, there are several steps that can be taken to overcome this as well as resources available for patients encountering these types of problems.

How can a patient find out if their individual fertility preservation treatments are covered?

The first thing a patient must do is to speak with their treating physician about the possibility of infertility and decide what treatment works best in regards to their age, diagnosis and cancer treatment regimen as well as where the fertility treatment can be obtained and what the potential costs are. It is always best to keep an open line of communication. Talk with a financial/benefits representative at the fertility practice and ask about specific details regarding insurance and costs up front. There potentially could be a reasonable payment plan that could be agreeable by both parties or the practice could provide a significant discount due to fertility treatments being a non-covered benefit. Also, make sure written confirmation is in hand regarding what the insurance will pay if any. Having all of the information up front can assist patients in making better decisions regarding how to handle this in regards to their own assets, which will ultimately avoid any surprises that may pop up just before or after any treatments have been obtained.

Are there financial assistance programs to help patients obtain treatment?

As mentioned above, some fertility practices provide payment plans and “treatment packages” at a single price and even offer financing options to make treatment more affordable by paying for it over time. There is a program available entitled, “Sharing Hope” that reduces the costs of fertility preservation for those patients that qualify. Sharing Hope provides discounted sperm banking services, access to fertility medications and discounted egg and/or embryo freezing services. Patients would have to ask the practice where their treatment would be received up front if they participate. Sharing Hope and other resources relevant to this topic are located in the Resource Appendix.

How and when should patients decide if costly fertility treatments are right for them?

Fertility treatments are often expensive and it may be difficult to even consider spending money on fertility preservation while also dealing with piles of medical bills and/or loss of employment income due to a chronic diagnosis. Nevertheless, it is wise to stress that each patient is different and each must weigh the importance of trying to preserve their fertility while thinking of the financial, physical and emotional costs encountered while undergoing cancer treatment.

The main thing to remember is that patients must have all of the information as to their options surrounding potential infertility so each can be proactive when deciding what is best for them and their family. Let it be known that many patients can preserve their fertility if they are knowledgeable and seek this valuable information from their physician as they can indeed take advantage of the latest technologies and financial assistance available.

Resource Appendix

PAF seeks to empower patients across the country to take control of their healthcare. If you would like further information about any of PAF's publications, to include those specifically cited in this guide, please contact our national headquarters toll-free at 1-800-532-5274 or visit us at www.patientadvocate.org for available downloads.

Patient Advocate Foundation

Seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of financial stability.

700 Thimble Shoals Blvd. Suite 200

Newport News, VA 23606

Phone: (800) 532-5274

www.patientadvocate.org

www.copays.org

www.colorectalcareline.org

Patient Advocate Foundation's Co-Pay Relief (CPR) A Patient Assistance Program

Provides co-payment assistance to insured Americans who financially and medically qualify.

700 Thimble Shoals Blvd, Suite 201

Newport News, VA 23606

Phone: (866) 512-3861

www.copays.org

American Cancer Society

Offers numerous resources, including printed materials, counseling for patients and their families, and information on lodging for people who may require treatment far from home. Contact your local chapter to find out about resources that maybe available in your community. Local ACS office may offer reimbursement for expenses related to cancer treatment including transportation, medicine, and medical supplies. Financial assistance is available in some areas.

1599 Clifton Rd

Atlanta, GA 30329

Phone: (800) 227-2345

www.cancer.org

Beyond the Cure

Beyond the Cure helps childhood cancer survivors integrate the cancer experience into their new life as survivors and successfully handle the challenges that are ahead of them and to celebrate survivorship.

Beyond the Cure is a program of The National Children's Cancer Society.

1015 Locust, Suite 600
St. Louis, MO 63101
Phone: (800) 536-6459
www.beyondthecure.org

Cancer Care

Is a national non-profit organization that provides free support services to anyone affected by cancer.

Phone: (800) 813 – HOPE
www.cancercare.org

Cancer Information Services in collaboration with the National Cancer Institute

Helps locate financial aid and/or emotional counseling services, as well as information on diagnostic procedures.

PO Box 24128
Baltimore, MD 21227
Phone: (800) 422-6237
www.cancernet.nci.nih.gov

Cancer Survivors' Fund

Cancer Survivors' Fund provides scholarships for young cancer survivors, give them a new purpose and meaning in life and enable them to continue their college education; provides prosthetic limbs to disadvantaged young adults; counsels, provides emotional support, and motivates young cancer survivors and channel their thoughts and dreams to a healthy and productive future; supports young survivors to become volunteers themselves, and give others courage and hope to develop a strong willpower to continue their fight with cancer.

Phone: (281) 437-7142
www.cancersurvivorsfund.org

Campaign for Home Energy Assistance: LIHEAP

Assist eligible low-income households in meeting the heating or cooling portion of their residential energy needs. LIHEAP dollars are distributed by local community action agencies, usually at the county level. The Salvation Army processes applications in many states.

Phone: (202) 783-5594 or (202) 783-5588

www.liheap.com

Catholic Charities

Provides callers with a local catholic charity to contact for financial assistance (varies depends on available funding)

Phone: (800) 919-9338

Centers for Medicare & Medicaid Services (CMS)

Federal Agency that administers Medicare, Medicaid and Child Health Insurance Programs; provides assistance with eligibility.

Phone: (410) 786-3000

www.cms.gov

Chai Lifeline

To provide financial assistance, housing, weekend retreats programs for the entire family living with a child with cancer or catastrophic illness, weekend retreats for bereaved families, holiday trips, insurance information as well as support to Jewish children who suffer from cancer and other life threatening illnesses.

151 West 30th Street

New York, NY 10001

Phone: (212) 465-1300 or (877) CHAI-LIFE

www.chailifeline.org

The Children's Cancer Association: Kids Cancer Pages

This is the first-ever national resource directory on childhood cancer. Recognized by the National Cancer Institute as "the most comprehensive guide for families currently available," this comprehensive directory is packed with information on all aspects of pediatric cancer. For families battling pediatric cancer – and the medical professionals who care for them – the Kids' Cancer Pages directory is a vital support tool.

Phone: (503) 244-3141

www.childrenscancerassociation.org

Childhood Leukemia Foundation

Provides children diagnosed with Leukemia under the age of 18 gift baskets, Toys R Us Certificates, Hip Hats, Camp Sponsorships, Valentine Parties, Wish List and Entertainment. The Childhood Leukemia Foundation will also assist in the cost of home care, transportation costs for the travel to chemotherapy or radiation treatment, and with the cost of medications. The guidelines for are flexible and are assessed individually. If there are unusually large expenses, these expenses are taken into consideration.

1608 Route # 88 West, Suite 203

Brick, NJ 08724

Phone: (800) CLF-7109 or (732) 840-7585

www.clf4kids.org

Children with Special Health Care Needs

Addresses issues related to innovative managed care arrangements, Medicaid managed care, policies, access to care, epidemiology of chronic childhood conditions, and the identification of children with special health care needs. The below link provides contact information for every state.

http://wdcrobcolp01.ed.gov/Programs/EROD/org_list.cfm?category_ID=SCH#K

Fertile Hope

This organization provides financial assistance through Sharing Hope, a program to help increase access to egg, embryo and sperm freezing.

Phone: (888) 994-4673

www.fertilehope.org

Katie Beckett Waiver Medicaid

The Katie Beckett Waiver, also known as the Deeming Waiver or the 2176 Model Waiver, is a federal waiver that is intended for children from birth to eighteen years of age with a chronic disability. It entitles children to Medicaid that would not otherwise qualify due to their parent's financial status.

www.cms.hhs.gov/home/Medicaid.asp

The Lance Armstrong Foundation

This organization seeks to inspire and empower people affected by cancer. From the moment of diagnosis, the Lance Armstrong

Foundation can assist one with the challenges and changes that come with cancer.

Phone: (866) 467-7205

www.livestrong.org

National Coalition for Cancer Survivorship

An organization to raise awareness of cancer survivors through education and publications.

1010 Wayne Ave. Suite 505

Silver Springs, MD 20910

Phone: (800) 650-9127

www.canceradvocacy.org

National Dissemination Center for Children and Youth with Disabilities

Serves as a central location for information regarding disabilities in children and youths, IDEA, no child left behind, research based information as well as Early Intervention program.

P.O. Box 1492

Washington D.C., 20013

Phone: (800) 695-0285

www.nichcy.org

National Institute of Health (NIH)

Young People With Cancer: A Handbook for Parents

This very comprehensive guide is designed to answer common questions about cancer in the young adults and children.

www.cancer.gov/cancerinfo/youngpeople

The SAMFund for Young Adult Survivors of Cancer

The broad mission of the SAM Fund is to assist cancer survivors in the United States between the ages of 17 and 35 with their transition into a successful post-treatment life. The foundation will distribute grants and scholarships in an effort to enable survivors to pursue their educational or professional goals, as well as offer outreach and information about the post-recovery transition to those approaching the end of treatment. The SAMFund seeks to provide the most extensive support possible, and to help young adult survivors move forward with their lives after cancer.

www.thesamfund.org

The State Child Health Insurance Program (SCHIP) through the Centers for Medicare and Medicaid Services

Requires states to provide health insurance to children from working families who qualify.

Phone: (877) 543-7669

www.cms.gov/schip

***Social Security Administration
Office of Public Inquiries***

6401 Security Blvd.

Room 4-C-5 Annex

Baltimore, MD 21235-6401

Phone: (800) 772-1213

www.ssa.gov

The Ulman Cancer Fund for Young Adults

Provides support networking groups advocacy and scholarships to young adults dealing with cancer.

4725 Dorsey Hall Drive, Suite A

Ellicott City, MD 21092

Phone: (410) 964-0202

www.ulmanfund.org

United Way

A nationwide directory of information referral services. When you need health counseling, legal aid, crisis intervention, home nursing care, substance abuse counseling and treatment, transportation or daycare for child or dependent adult.

Phone: (800) 411-8929

www.unitedway.org

Works Cited

A Guide to the Early Intervention System. Patient Advocate Foundation. (2002). <http://www.patientadvocate.org>

A Greater Understanding: Financial Assistance & Debt Crisis Intervention. Publication No. 1. Patient Advocate Foundation. (2003).

A Greater Understanding: Understanding Your Insurance Plan: Usual, Customary and Reasonable Charges. Publication No. 2. Patient Advocate Foundation. (Rev. 2006).

A Greater Understanding: Interpreting Your Explanation of Benefits (EOB). Publication No. 3. Patient Advocate Foundation. (2003).

A Greater Understanding: Social Security Disability (SSDI) vs. Supplemental Security Income (SSI) and Subsequent Entitlements. Publication No. 4. Patient Advocate Foundation. (2003).

A Greater Understanding: Health Insurance for Young Adults: Why you need it and How to keep it. Publication No. 6. Patient Advocate Foundation (2003).

A Greater Understanding: Help! I'm Uninsured. Publication No. 9. Patient Advocate Foundation. (2005).

A Greater Understanding: Help! I'm Underinsured. Publication No. 10. Patient Advocate Foundation. (2006).

Cancer and Fertility Resource Guide. Fertile Hope. (2007). www.fertilehope.org.

CMS Publication # CMS-02179. (2003).

Compliance Guide to the Family Medical Leave Act. WH Publication No. 1421. United States Department of Labor. (1996). www.dol.gov

Diagnosis. Wikipedia, the free encyclopedia. (2007). <http://en.wikipedia.org/wiki/Diagnosis>

Disability Determination Process. Social Security Administration Online. (2004). <http://www.ssa.gov/disability/determination>.

Government Resources for ALS Patients. The Amyotrophic Lateral Sclerosis Association. (2004). <http://www.alsa.stl.org/view-story.php>.

HHA-SSA Publication No. 05-10029

How to Cope With Your Child's Illness. Cincinnati Children's Hospital Medical Center. (2007). <http://www.cincinnatichildrens.org/about/patient/coping/>.

Issues in Measuring Quality of Life in Childhood Cancer: Measures, Proxies, and Parental Mental Health. The Journal of Child Psychology and Psychiatry and Allied Disciplines (2001), 42: 661-667. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=80534>.

Managed Care Answer Guide. Patient Advocate Foundation. (2nd Ed. 2004).

Medicare and Other Health Benefits: Your Guide to Who Pays First. Publication No. CMS-02179. (2003). www.cms.gov.

Medicare and You, 2004. Publication No. CMS-10050. U.S. Department of Health and Human Services. (2004).

Peer Influences in Pediatric Chronic Illness: An Update. *Journal of Pediatric Psychology*. (1992), 17(6), 775-784. <http://jpepsy.oxfordjournals.org/cgi/content/abstract/17/6/775>.

Respite Care. Rainbow Rehabilitation Center. (2007). <http://www.rainbowrehab.com>.

United States Government/Resources. About.com. (2007). <http://usgovinfo.about.com/library/weekly/aa061800b.htm>.

Your Guide To The Disability Process. Patient Advocate Foundation. (1st Ed. 2004).