



CANDLELIGHTERS

CHILDHOOD • CANCER • FOUNDATION



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Candlelighters
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QUARTERLY NEWSLETTER

FALL 1999

CORD BLOOD TRANSPLANTATION

by Leonard Johnson, M.D.

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CORD BLOOD

TRANSPLANTATION

by Leonard Johnson, M.D.

The fact that cord blood (or blood from the placenta) contains stem cells that are identical to those present in bone marrow was first demonstrated over two decades ago. Subsequently it was shown that these cord blood cells could be stored for a long time. These two findings led to the first use of cord blood to successfully treat a five year old boy with a congenital form of marrow failure (called Fanconi Anemia), using cord blood from the birth of his sister, who was identical on tissue typing. By

A New Vision:

For the past three decades, childhood cancer patients, families, and local support groups have depended on Candlelighters to assist in many areas. As we enter our fourth decade, our new vision *"To deliver superior childhood cancer*

1993 it had been shown that cord blood banking for unrelated transplantation was possible with the development of the first cord blood bank at the New York Blood Center. The ability to bank cord blood increases the chances of finding a source of stem cells for patients who could benefit from treatment by stem cell transplantation, particularly in certain ethnic groups under-represented in the unrelated bone marrow donor registries. The stored cells are immediately available in contrast to the time it takes to identify and obtain marrow from an unrelated marrow donor registry.

Two types of cord blood transplants can be performed: (i) using cord blood from a



sibling in a family in which there is already a child affected by a disease which might benefit from stem cell transplantation; and (ii) using stem cells obtained from an unrelated donor cord blood bank. The diseases for which cord blood transplantation has been used are exactly the same as those treated by bone marrow transplantation:

continued on page 10...

by Mike O'Brien, President

information and support with professionalism and compassion" will guide us to serve you better. To do this, we will capitalize on the advantages of technology and continue building relationships with other national-level cancer organizations. We

do all this because we truly love our children. I encourage everyone to visit us on the Internet at www.candlelighters.org, to email us at: info@candlelighters.org and watch us grow into the 21st century. I look forward to serving you!

Candlelighters' National Office Names New Executive Director

The Candlelighters Childhood Cancer Foundation (CCCCF) announced at their recent Board meeting (10/30/99) the appointment of Ruth Hoffman as Executive Director. The announcement was made by Mike O'Brien, foundation President.

Ms. Hoffman brings to CCCCf a wealth of experience from the pediatric oncology non-profit sector. She was former Executive Director of ChildCan, The Childhood Cancer Research Association located in Southwestern Ontario, Canada; Chair



of OPACC (Ontario Parents Advocating for Childhood Cancer); Parent representative on the Executive Committee of POGO (Pediatric Oncology Group of Ontario) and childhood cancer representative on the Education Committee of Cancer Care Ontario.

Ms. Hoffman sat on numerous task forces reporting back to the Ministry of Health addressing gaps in childhood cancer service, specific to treatment modalities, psychosocial impact of disease and long term follow up issues.

A graduate of Psychology and Education from the University of Western Ontario and former teacher, Ruth relocated to the DC area this past January with her husband, Dr. Eric Hoffman who was appointed at that time as Director of Genetic Medicine at Children's National Medical Center.

Ruth is the mother of nine children in a blended family, including her 19 year old daughter Naomi, who is a 12 year survivor of AML, now attending college at the University of Ottawa.

Tribute to Carolyn Corry

It is with great sadness that the Candlelighters Board of Directors would like to inform its members of the tragic death of our Executive Director, who died in late September of a ruptured brain aneurysm. Carolyn Corry had been appointed executive director of Candlelighters only last December. Previously she had been active in Democratic politics, environmental and women's issues and creative arts in Northern Virginia, Richmond, and Charlottesville. She had directed Planned Parenthood offices in Washington and

Charlottesville and helped organize the 1998 National March Against Cancer in Washington DC.

While Carolyn's time with Candlelighters was unfortunately brief, she will be remembered by the group leaders who sensed her commitment to our cause at the 1999 group leader's conference and at other meetings. Contributions in her memory are being made to Candlelighters Childhood Cancer Foundation by friends and family.

Spinoza... the Bear Who Speaks from the Heart helps children with cancer and their families

Spinoza® ...the Bear Who Speaks from the Heart™ is a therapeutic tool in the form of a teddy bear. He's a cuddly, stuffed 17" bear with a tape player tucked discretely inside, and comes with a library of 9 cassette tapes. These tapes cover topics such as relaxation, self-esteem, imagination, as well as a powerful tape on grief and loss. Spinoza has helped to calm and comfort over 17,000 children across America.

Spinoza's "buddy bear project" is a community based project that focuses its attention on children who are going through a profound illness or crisis situation. Children are referred to us by facilities who provide their first name, age, hometown, and a brief diagnosis. Spinoza's "buddy bear project" then contacts local community service organizations such as The American Legion Family, Lions, Jaycees, etc. and the clubs then vote on sponsoring the children. There is absolutely no cost to the children's families or referring facilities/agencies. To find out more about Spinoza's "buddy bear project" see our website at www.spinozabear.com or call **1-800-CUB-BEAR** to speak with the coordinator for your state.

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We're on the Web
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We welcome letters to the editor: poetry, photos, short stories, viewpoints, and other material from readers. Articles are selected for space and may be edited. The contents of this newsletter are copyrighted and no part may be reprinted without prior written permission from the publisher.

The Candlelighters Childhood Cancer Foundation is an international organization providing support, education, and advocacy programs for families of children with cancer, survivors of childhood cancer and the professionals who care for them.

Hepatitis C in survivors of childhood cancer

Nancy Keene and Kevin Oeffinger M.D.

Hepatitis C (HCV) is an inflammation of the liver caused by the hepatitis C virus. HCV is spread by blood transfusions (given prior to effective testing of blood products), sharing needles for intravenous drug use, and less commonly, through sexual intercourse. Nearly 4 million people in the United States are infected with the hepatitis C virus, making it the most common chronic blood-borne infection in the country.

Before 1992, a laboratory test to identify blood carrying the hepatitis C virus was not available, and some children and teens with cancer received infected blood. Since more effective tests for the virus have been used by blood banks since 1992, the current risk of getting HCV from a single blood transfusion is very small, only 1 in 100,000.

If you are infected with the hepatitis C virus, there are five possible outcomes:

- Your body’s immune system may eliminate the virus and you will have no further problems.
- You may have a life-long infection, but your liver sustains no damage.
- You may develop inflammation of the liver, with or without symptoms.
- You may develop progressive inflammation and scarring of the liver. When this scarring (fibrosis) is spread throughout the liver, it is called cirrhosis. This process occurs over many years, and usually results in symptoms. It can eventually lead to liver failure.
- In rare cases, liver cancer develops after years of chronic hepatitis C and cirrhosis.

Signs and symptoms

Because hepatitis C can silently damage the liver, a survivor may not be aware of the infection until many years later when late complications of liver disease cause symptoms. Though most people with hepatitis C have no symptoms at the onset of the infection, some may experience jaundice (yellowish eyes and skin), fatigue, loss of appetite, nausea and vomiting, low grade fever, pale or clay colored stools, dark urine, itching, or diarrhea.

Your yearly follow-up examination should include a discussion about your liver and history of blood transfusions.

Screening

Your yearly follow-up examination should include a discussion about your liver and history of blood transfusions. You should get tested for HCV if any of the following apply to you:

- If you have been notified that you received blood from a donor who later tested positive for hepatitis C
- If you have had a stem cell or bone marrow transplant
- If you received any blood products before July, 1992
- If you had solid organ transplant before July, 1992
- If you have signs or symptoms of liver disease (e.g., abnormal liver enzyme tests or enlarged liver)

Many institutions recommend a blood test (ALT, alanine transaminase) every 2 to 5 years to monitor liver function. During your annual physical examination, your health care provider should palpate (feel)

your abdomen to check for an enlarged liver. If you had a stem cell or bone marrow transplant, you should also have a test for iron overload.

...Continued on page 9

Michael J. O’Brien is the new President of the Candlelighters Childhood Cancer Foundation, succeeding Patricia Deasy-Spinetta.

O’Brien, a senior training manager for the Department of Defense, has been president of "Parents and Children Fighting Cancer," a local Candlelighters Chapter assisting families that receive medical care at Walter Reed Army Medical Center in Washington DC, since 1995. He has rebuilt that organization, establishing a solid group to serve the military community. Mike and his wife Colleen have three daughters. The eldest,

Morgan, who spoke at the Lincoln Memorial during the 1998 MARCH against Cancer is a ‘two-time’ survivor of ALL.

Other officers for the year 1999-2000 are Lynn Thompson, Mobile, Alabama, First Vice President; Robert Wilbur, Washington, DC, Second Vice President; Kenneth Phillips, Colorado Springs, Colorado, Treasurer, and Barbara Rennhoff, Pittsburgh, Pennsylvania, Secretary.

New board members, in addition to Mike O’Brien, are Christa Cohan, Falls Church, Virginia; Steven Payne, Atlanta, Georgia; Lisa White, Bluefield, Virginia (formerly from Utah); and Kimbra Gish Wilder, Nashville, Tennessee.

Candlelighters thanks Pat Spinetta for her work during this year of transition for the national office

Candlelighters' New Resource Manual for Support Group Leaders

Funded by a generous grant from the *Arthur K. Watson Charitable Trust*, Candlelighters Childhood Cancer Foundation is excited to announce the impending publication of **YOU ARE NOT ALONE**, a sourcebook for people organizing mutual support groups for families of children with cancer. Candlelighters, founded and governed by parents of children with cancer, and working closely with medical and social work professionals, produces a series of newsletters, books, conferences and other services that are available to children with cancer, their families and local parent support groups.

YOU ARE NOT ALONE is written for parents of children who are interested in starting, leading, improving or just being a part of a mutual support group. It also will be useful for medical and social work professionals who are interested in helping parents organize such groups. It is presented in a spiral bound format so new materials can be added and illustrations

materials can be added and illustrations and exhibits copied for local use.

YOU ARE NOT ALONE addresses the following issues: what challenges do parents of children with cancer face; how can mutual support groups be helpful to parents in meeting these challenges; what steps are involved in forming a new group; what kinds of programs or services can groups offer parents; what skills do people need to keep a group running efficiently; how formally should a local group be structured; how can groups work best with the medical staff and other community organizations; where can group leaders go for more assistance; and what is the role of the National Candlelighters Childhood Cancer Foundation.

YOU ARE NOT ALONE has been written by Mark Chesler (a parent of a survivor of childhood cancer and a former President of Candlelighters, who also is a prominent researcher on psychosocial issues affecting families of children with cancer) and Sara Eldridge (a medical social worker who visited many local childhood cancer family support groups and group leaders).

Publication of the Sourcebook is scheduled for early January. It will be distributed immediately without charge to all local parent support groups on the Candlelighter mailing list. To ensure that you receive a copy, email Candlelighters at: info@candlelighters.org or call: 301-657-8401.

Cost to other interested groups is: \$15.00

A special thank you to Dr. Mark Chesler and Sara Eldridge for the dedicated work that has gone into the writing of this important resource.

A Young Knight Struggles

*A young knight struggles against death,
His road long and painful,
His movements quick and sudden,
His enemy undefeatable,
But still he struggled on
Through the pain and agony
Over and on the road
Towards a light that was his goal.
And every step was harder than the last.
And every movement was countered by pain,
But on strove the valiant knight.*

*Knowing not defeat, fearing nothing
he moved on.*

*And when his armor fell,
crumbled on the floor*

*He continued on-
In vain*

*For the enemy was still there,
And it struck him down.*

*But to the end
He clutched his sword!*

The knight was Terry Fox;

*The road his Marathon;
The light his hope*

For the cure.

*The pain was real;
The enemy cancer;*

*His armor was his strength
That lasted him so long.*

But his sword?

His sword was his heart.

*And even today we honor the knight who
struggled for the light,*

*his hope,
The cure.*

Written by Kyle Levesque.

Grasmere School

Alberta Beach, Alberta

Our Kids write....

.....My name is Ruth. I am 14 and I am a **SIBS**. You are probably wondering what I mean by **SIBS**. Before I explain, I should tell you that I have a four year old brother with leukemia. Siblings of cancer patients often know the feeling of being the 'Forgotten Child'. Being forgotten at holidays, birthdays, vacations, family trips, fundraisers, and even at home is very common for the siblings of a child with cancer. When my brother was diagnosed, my name was forgotten in Christmas cards and people would rush past me to exclaim how much my brother has grown. That used to get to me, but now it doesn't. Why is that, you say. Three months after my brother was diagnosed, my family went to a special camp called Camp Okizu. Camp Okizu is a camp of children with cancer and their families. There, I learned that I was a **SIBS**,

meaning Special and Important Brothers and Sisters. I was special and I was important. Not only did I get that, but I met kids who were also **SIBS** and I didn't feel so alone and ashamed of my feelings. I made friends with a 14 year old who is undergoing treatment for leukemia after having a relapse. I also made a friend who had leukemia, was considered cured and relapsed twice after that. Believe it or not, he is now OFF treatment and doing great! Being friends with a patient and a miracle helped me realize what he could be feeling. I was surrounded by people who understood and who cared. Most importantly, I was around people who didn't pity my situation, people who were genuine.

SIBS has a whole new meaning for me. You don't have to go to camp to be a Special and Important Brother or Sister, you already are! By Ruth Osorio

LOW-COST OR FREE HEALTH INSURANCE FOR KIDS IS HERE

Maternal and Child Health Information:

CHIP (Child Health Insurance Program) Enrollment:

The White House and the Department of Health and Human Services (HHS) has announced a new health insurance program which is beginning to take hold across the Nation. Each state participates on a voluntary basis and has its own program. The program is unique in that it makes health insur-



ance coverage available to children in working families. With approximately one million children already enrolled in the program, the HSS has indicated that they are well on their way to enrolling their target of 2.5 million children by the year 2000. The NGA (National Governors' Association) also reported that in the first month of the 'Insure Kids Now' hotline operations, more than 41,000 parents interested in enrolling their children in state health insurance programs called

for information. For information on:

1/What the health insurance pays for; 2/Who is eligible, 3/Which states are involved, 4/ Who to contact and where to get more information, check out the website at: <http://www.insurekidsnow.gov/> or call 1-877-KIDS-NOW. This is a free call.

' Don't let your kids go another day without health coverage.'

The Americans With Disabilities Act

by Mary Helmreich

The Americans With Disabilities Act 1990 became effective in 1992. It grants persons with disabilities access to insurance and the workplace, i.e., they cannot be denied insurance or employment due to a disability. Today, 75-80% of the general population does not know what this is.

ADA: What It Means for Childhood Cancer Families: The Americans with Disabilities Act (ADA) is a federal civil rights law that grants cancer survivors lifetime comprehensive access to employment and education. The law also grants some protection to the cancer survivor's parents, siblings and spouse.

Under the ADA, a childhood cancer survivor is a person with a disability. As a disability, a cancer diagnosis can no longer be used

against an applicant in applying for

a job. Likewise, an employer cannot deny health insurance and other benefits to a person who has had cancer unless he denies benefits to all employees. Once employed, a cancer survivor may not be singled out and refused benefits that other employees receive.

Similarly, a parent of a child with cancer may not lose benefits or health coverage due to the child's diagnosis. Parents, spouses or siblings cannot be denied employment opportunities or benefits because of their relationship with a cancer survivor. Furthermore, employers may not refuse to hire or fire employees with dependents who have cancer due to future increases in health care costs or because the dependent is not covered by the employer's health insurance plan. For the childhood cancer survivor, the ADA provides

by federal law the right to pursue employment and job promotion, equal opportunity in the workplace,

equal opportunity to obtain health care services and insurance, equal access to education and military service, and equal access to society's benefits.

Advocacy Resources:

- 1/ Daniel Fiduccia, ADA expert and long-term survivor, 408-725-8787, DFIDUCCIA@aol.com
19907 Beckman Place, Cupertino, CA 95014-2452
- 2/ Grace Powers Monaco, JD, founder of Ombudsman Program for children and adults, 804-580-2600, gpmonaco@rivnet.net P. O. Box 595, Burgess, VA 22432
- 3/ Publications on the ADA, U.S. Equal Opportunity Commission, 800-669-EEOC
- 4/ The U.S. Department of Justice, 800-841-0301

Group leaders Conference 2000 Las Vegas Nevada

By: Eleya Olivas-Simon, CCCSN Executive Director

Where : The group leaders conference 2000 will be hosted by the Southern Nevada chapter in Las Vegas. It will be held the weekend of May 19th – 21st, and the registration cost is \$100 per person.

Who should attend? Group leaders, board members, staff, new chapters, existing chapters and anyone with a commitment to improving the lives of children with cancer. Chapters who have never attended in the past are strongly encouraged to attend.

Why should you attend? This conference gives everyone the opportunity to share ideas, information, knowledge and meet others who are working at the same goal. By brainstorming and networking you will build friendships and mutual

respect. Each organization and individual brings a new light to the Candlelighter organization. With the new National Candlelighters board and executive director, everyone's input is necessary.

What to expect: A preliminary schedule of topics includes: How to develop a successful volunteer program; Developing a case for giving; Fundraising; Major gift campaigns and planned giving; Media and Advertising; Programs & Services; Grant writing; Leading the non profit org; donor relations; budgeting and technical support. All the workshops will be covered by experienced non-profit and business professionals. The Topics will be geared for all stages

Save The Date

of development, whether you're just starting your chapter or would like to bring it to the next level. You can register by mail 3201 S. Maryland Pkwy #512 Las Vegas, NV 89109, on-line www.citycare.org by fax. We take visa or MasterCard. Early registration is Jan. 1st - Feb. 1st Cancellations received by March 1st will receive full refund. Cancellations after March 2nd will be eligible for \$20.

If you have any questions regarding the conference you can email Eleya Olivas -Simon at: eleya@bigplanet.com

Group Leaders Conference '99 Summary

by Mary Helmreich

Candlelighters Annual Group Leaders Workshop was held April 30, May 1 and 2, 1999 in Melbourne, Florida hosted by Carrie McCarthy and Linda Martin of Candlelighters of Brevard, Inc., their board of Directors and volunteers. Over 34 attendees from 13 states attended and received the gracious, warm and sunny hospitality of our hosts. Carrie and Linda added "retreat" to the main agenda, in their desire to offer group leaders many fun diversions and activities in addition to an effective "nuts and bolts" sessions. Group leaders were greeted with welcome gifts and goody bags upon arrival, door prizes were drawn during morning and afternoon sessions, and several interactive seating arrangements allowed all attendees to mix and mingle.

The late Executive Director Carolyn Corry and President Pat Spinetta addressed the group on National's behalf. Highlights of the workshop agenda included: an excellent presentation by a radio personality who offered insight into how to best utilize radio; a newspaper editor explained what was news to print media and how to establish a relationship with a reporter or newspaper; grant writing specifics from a professional; how to attract and keep volunteers; break-out sessions related to financial issues, 501 (c)(3) and the IRS; brainstorming for established groups, and a final stress breakout. Before the end of the first day we were treated to massage, a luau hosted by the Brevard Board, and a midnight run to Ron Jon's Surf Shop! Throughout the weekend, group leaders

sought each other out for guidance and support and made a point of sharing information and resources openly and willingly. Sunday morning, Gigi Thorson presented a session on computers in a nutshell, but more importantly set everyone up on a list server so that since the workshop, we are all on daily email contact with one another.

The Las Vegas group volunteered to host the next workshop 2000 and is currently preparing a mailer to go out to groups and interested leaders. The CURE group, Rochester, NY has volunteered to host in 2001.

Special thanks to: Carrie McCarthy, Linda Martin and Candlelighters Brevard Inc. for an incredible conference.



Book Review: Childhood Cancer by Honna Janes Hodder and Nancy Keene

Childhood Cancer, the most complete parent guide available, includes detailed and precise medical information about solid tumor childhood cancers, including neuroblastoma, Wilms tumor, liver tumors, soft tissue sarcomas, and bone sarcomas. In addition, it offers day-to-day practical advice on how to cope with procedures, hospitalization, family and friends, school, social and financial

issues, communication, feelings, and, if therapy is not successful, the difficult issues of death and bereavement. Obtaining a basic understanding of topics such as medical terminology, how drugs work, and common side effects of chemotherapy, and how to work more effectively with medical personnel can only improve the quality of life for the whole family. Parents who read this book will encounter medical facts simply explained, advice to ease their daily lives, and tools to be strong advocates for their child.

..review by Amazon.com

International Conferences:

**Childhood Cancer and the Family:
Together in 2000**
**A Childhood Cancer Foundation ~
Candlelighters Canada Conference**
August 18 - 20, 2000
Toronto, Ontario

The 4th international conference is co-hosted by the Parent Groups of Ontario and The Childhood Cancer Foundation~Candlelighters Canada.

Dr. Bernie Seigel will give the opening keynote address.

Other well known speakers include: Sr. Frances Dominica, an international expert on children's palliative care and hospice care; Dr. Lauren Woodhouse, a laughter therapist and Dr. Mark Greenberg who will speak

on long term effects.

This child and family conference will bring Candlelighters into the next century. Special events are planned for the children who will be spending their days in recreational programmes designed by camp staff as well having special sessions for them during the conference.

*Information can be obtained from:
Candlelighters Canada,
55 Eglinton Avenue East, Suite 401
Toronto, Ontario M4P 1G8,
Ph:416 489-6440,
Fax 416 489-9812
Email: staff@candlelighters.ca
www.candlelighters.ca*

Mark Your Calendar!



Children and Grief

The 18th International conference on Death and Bereavement is to be held at King's College, London Ontario Canada. The theme of this Y2K event is: Death and Spirituality. Conference dates are: May 15-17, with pre-conference workshops May 13 and 14th. For a summary of last year's event in addition to a list of audio and video tapes available, please see: <http://www.wwdc.com/death/resources.html>

A unique offering of a compelling educational television series – Journey of Hope, Helping Children Cope with Death is also now available on videotape. The series examines the effects of a childhood loss on the cognitive and emotional functions; explains how to find that 'teachable moment'; examines the role of siblings and explains the importance of memorial events, books, journals and photos.

Information on the conference or resource materials can be obtained by writing to:
John D. Morgan Ph.D
266 Epworth Avenue
London, Ontario, Canada N6A 2M3
Tel 519-433-3491
Fax: 519-432-0200

Email: jmorgan@julian.uwo.ca
Or visit the website at: <http://www.wwdc.com/death>

ICCCPO Transcends Borders, Unites Hearts

Ever since Candlelighters was founded almost 30 years ago, support groups for parents of children with cancer have been an important step in the care of the child with cancer—and a movement that is still growing. **The International Confederation of Childhood Cancer Parent Organizations (ICCCPO)** was formed in 1994 in Valencia, Spain, as a membership organization for these support groups

around the world. ICCCPO acts a voice for families to international health and social-service agencies; helps countries without organized parent support groups to form them; and advocates for improved care for children with cancer. CCCF is a founding member. As horrific as it is for families in the United States to face a diagnosis of cancer in their child, in many parts of the world the situation is

by Mark Chesler, PhD

even more overwhelming. For example, the current survival rate for childhood cancer overall in the U.S. is close to 75%, but in many parts of Latin America, Asia, and Africa, it is only about 25%. In many of the less-wealthy nations of the world, there

...continued at bottom of next page

Living Day By Day: A new support group for parents who have lost a child to cancer

by Ruth Hoffman

Living Day By Day is a new support group for parents who have lost a child to cancer. The first gathering of this pilot program will take place in the Baltimore/DC area on Sunday, December 5 from 6:00 p.m. to 8:30 p.m. at the NIH. Sponsored by One Voice Foundation, Inc., the group is an expansion of the 18-month-old online grief support group DayByDay Online.

"Our goal is to take this concept of bereaved family support

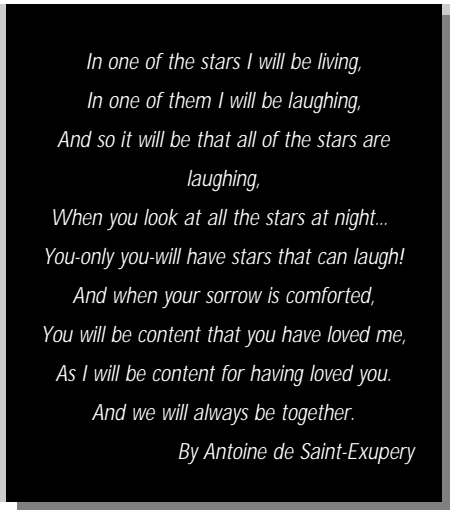
to nine additional cities across the country by the end of 2000," said Gigi Thorsen, Director of Living Day By

Day and founder of DayByDay Online. "It is vital to include supporting the bereaved family when addressing the needs of all families of children with cancer, since around 35% of these families have children who have died. We would like to work collabora-

tively with Candlelighters groups across the country in getting these chapters launched," she added.

In the works is a compilation of a group model and mission statement, variations on the monthly or quarterly meeting, information on locating bereaved families, finding a meeting location, letterhead and business card templates, etc.

If you or your group is interested in finding out more about Living Day By Day, please contact Gigi Thorsen at gigi@lgcy.com or at 801-944-4553, or Bob McQuin at 1-800-782-3494 ext. 2737.



Candlelighters' Publications:

Free publications to childhood cancer families and those professionals who support and care for them.

- Know Before You Go, 1998, Funded by SmithKline Beecham and the FreddieMac Foundation: this book assists families in their journey through treatment
- Educating the Child With Cancer, 1993, Handbook endorsed by the American Federation of Teachers and the National Education Association

- The Candlelighters Guide to Bone Marrow Transplants in Children, 1994
- CCCF Bibliography and Resource Guide, 1994, Supplement 1997
- Introduction to the Americans With Disabilities Act: A Guide for Families of Children with Cancer, 1995
- You Are Not Alone, available Feb. 2000, funded by a generous grant from the Watson Foundation, this sourcebook is for people organizing mutual support groups for families of children with cancer.

Female Hodgkin's survivors have an increased risk of developing breast cancer at an early age. Although there is not yet consensus on the schedule for follow-up, if you were treated with mantle radiation between the ages of 10 and 20, many institutions recommend monthly breast self examinations, a yearly breast examination by a healthcare provider, and mammograms every other year starting ten years after treatment or by age 25, and every year after 35.

Continued from bottom of previous page...

is a lack of adequately trained physicians (both in oncology and primary care) and a lack of funds for basic chemotherapy. Public health conditions are poor; basic sanitation measures often do not exist. This puts immunocompromised children at enormous risk. Often a painful choice must be made to use meager funds to prevent cholera, typhoid fever, and other public health hazards rather than treat childhood cancer. In many areas, parents who have a child with

cancer must travel long distances for treatment, with few or no vehicles available in their town and no public transportation. Some children can't get access to oncologists and the child therefore ends up being treated, if at all, by unconventional practitioners such as faith healers.

ICCCPO is working to share resources and information so that every child in the world can have access to potentially life-saving treatment. They are also

working closely with the International Society of Pediatric Oncologists (SIOP). As the ICCCP Newsletter states, "Hand in hand, we can make a difference!" The Confederation now has 38 member nations. For more information, contact the ICCCP Secretariat, 55 Eglinton Ave. East, Suite 401, Toronto, Canada, M4P 1G8 Phone: 416-489-6440/ Fax:416-489-9812.

...Continued from page 3 ...

Any abnormal findings should result in a referral to a gastro-enterologist for further evaluation and treatment.

Treatment

There is no specific treatment for acute hepatitis. Rest may be recommended during the acute phase if symptoms are severe. The acute infection usually disappears three to four months after symptoms begin. About 50 percent of people infected with hepatitis C develop chronic hepatitis.

Chronic hepatitis can be treated with a number of medications. Alpha-interferon, which stimulates the immune system to fight the infection, and ribavirin, an anti-viral antibiotic, are usually given together. This combination treatment is effective in up to half of patients. These drugs are not licensed for persons under 18 years of age. Children with hepatitis C should be referred to a children's specialist in liver diseases.

Because the liver can become so damaged that it can no longer perform its crucial functions, some people who have had hepatitis C for many years may need a liver transplant.

Survivors who have had chronic hepatitis C and develop cirrhosis (scarring of the liver) may develop a type of liver cancer called hepatocellular carcinoma. The chance of developing this cancer is greatly increased in those who drink alcohol. To screen for this type of cancer, a blood test (alpha-fetoprotein) may be periodically checked in the survivor with cirrhosis.

If you have HCV, you can do the following to protect your liver:

- Don't drink alcohol – it greatly increases damage to the liver. This includes even occasional beer or wine.
- Don't use over-the-counter medications, such as Tylenol (acetaminophen) or Advil (ibuprofen), herbal or dietary aids, or prescription medications without first discussing it with your doctor. Many of these can cause more damage to the liver.
- Get vaccinated against hepatitis A and B.
- See your doctor regularly.

Because the infection can be spread to a partner by sexual intercourse, it is important to use barrier protection, such as condoms.

Unfortunately, there is not a vaccine against hepatitis C. Thus, a spouse (or sexual partner) of a survivor with hepatitis C can also get the infection. Because of this risk, the spouse (sexual partner) should be periodically screened for hepatitis C.

Rarely, hepatitis C can be transmitted to an infant during pregnancy. It is important that the female survivor with hepatitis C tell her obstetrician, pediatrician, or family physician about the infection.

Many people with HCV infections find comfort in participating in a support group. These are available in many communities since the disease is now so widespread.

For more information on Hepatitis C, read the frequently asked questions on the US Center for Disease Control Hepatitis C website: <http://www.cdc.gov/ncidod/diseases/hepatitis/c/faq.htm> or call them at (888) 4-HEP-CDC.

Nancy Keene is the author of Childhood Leukemia, Childhood Cancer (with co-author Honna Janes-Hodder), Your Child in the Hospital, and Working with your Doctor. She is also presently co-writing a book for survivors of childhood cancer with Wendy Hobbie RN and Kathy Ruc-

cione. Nancy is the mother of an 11 year old daughter Kathyrn who is a survivor of high risk ALL and 9 year old daughter Alison. Kevin Oeffinger M.D. directs a multidisciplinary program for young adult survivors of childhood cancer at UT Southwestern at Dallas. He enjoys backpacking, running and hiking with his wife Patty, son Daniel (16) and daughter Ashley (13).

Special thank you to Nancy and Kevin for this edition's column focus on Long Term Follow Up Care.

Research Volunteers needed :

If your child has been diagnosed with cancer and is receiving any therapies not prescribed by his or her doctor (e.g., home remedies; special foods and drinks; prayer and religious healing; vitamins; energy healing; visits to traditional healers), I would be very interested in talking with you about your experiences, knowledge, and health practices. Through this research, I hope to compile information that will help doctors provide better services to children with cancer. I am a doctoral candidate at the University of Pennsylvania, and I am seeking to meet particularly with parents in the Philadelphia area. Our conversations will be carried out with strict confidentiality and anonymity. Please contact Yanna Lambrinidou at ylambrin@sas.upenn.edu or 215 413-2552. Thank you.

Resources:

CANCERcare: Comprehensive Guide to Cancer Resources now available on line. 'A Helping Hand: The Resource Guide for People with Cancer, Cancer Care's comprehensive directory of cancer-related organizations, service and information providers, is now available online at the Cancer Care web site at: www.cancercare.org

L&A Publishing/Training has developed a line of reader-friendly tip cards and booklets on the **consequences of brain injury** in children and adolescents. Catalog: L & A, 22 Keewaydin Rd., Wolfeboro, NH 03894/603-569-3826, e-mail mlashnh@worldpath.net

The **National Retinoblastoma Support Group** has a new address: P.O. Box 317, Watertown, MA 02471/800-562-6265 or 617-972-7441. The group offers support, national networking for parents, newsletter.

New from the **National Cancer Institute: Taking Part in Clinical Trials: What Cancer Patients Need to Know**, a reader-friendly booklet. Includes glossary. Call 1-800-4-CANCER or visit <http://www.nci.nih.gov> on the Web.

A Hospital Trip with Dr. Bip consists of a **video and coloring books** created for children aged two to 10 by a pediatric anesthesiologist. In the video (12 min., \$14.95), Dr. Bip, an animated character, gives an easy-to-follow trip to the hospital and explains pre- and postoperative routines. A day-surgery version is also available. Coloring book (\$15/dozen) is available in English or Spanish. Shipping/handling \$3.50, quantity discounts. Information or orders: Kidz-Med, Inc., P.O. Box 490862, Miami, FL 33419-0862/305-361-6378.

The **Starbright Foundation**, a non-profit organization chaired by Steven Spielberg and Gen. Norman Schwarzkopf, has launched a **new video series**, "Videos with Attitude," for **preteens and teens** with serious illness and for those who care for them. In an entertaining, MTV-type of style, kids offer advice on coping with serious illness, doctors, nurses, hospital life, etc. The two titles are "Plastic Eggs or Something?: Cracking Hospital Life" and "What Am I, Chopped Liver??" Free upon request by a young person with serious illness (whether newly diagnosed or a survivor); purchase price for health professionals is \$35 each video. Discussion guide included. Visit www.starbright.org, call 310-442-1560 ext. 10, or write Starbright Foundation, 1990 South Bundy Dr., Suite 100, Los Angeles, CA 90025.

Adult Survivors of Childhood Cancer--The Dana-Farber Cancer Institute is forming focus groups and an advisory board to develop educational health programs for adult (aged 18 and older) survivors of childhood cancers. If you are interested (whether you live near Boston or not) and would like to be contacted, call 617-632-5333 or fax 617-632-4858, leaving your name, address, and telephone number. Dana-Farber will be hiring some adult survivors of childhood cancer for a study about smoking this focus group. You must have been diagnosed before age 25, be able to attend weekly meetings in Boston, be interested in a half-time position, and have good peer-counseling skills. Call 617-632-2182.

...continued from page 1

cancer (particularly leukemia), bone marrow failure (particularly aplastic anemia), diseases of the immune system, and a variety of genetic diseases.

There was initial concern that the volume of blood and number of stem cells that can be obtained from a cord blood unit (which averages less than half a pint) might not be sufficient to enable successful transplantation in adult patients. Successful transplants, however, have been reported in adult patients weighing over 180 pounds. With appropriate treatment prior to cord blood transplantation, this will probably not prove to be a major problem.

A major advantage of using cord blood as a source of stem cells is that the severity of graft-versus-host disease, a major complication of marrow transplantation, appears to be less, even in mis-matched transplants. Children who have transplants using matched sibling cord blood appear to have less than a 10% chance of developing graft-versus-host disease, significantly less than observed using bone marrow from the same type of donor. The overall incidence of graft-versus-host disease in unrelated transplants, not unexpectedly, is higher; but the incidence of the most severe form also appears to be markedly less than that observed with using marrow from an unrelated marrow donor. Further experience will be needed, however, to determine the exact degree to which unrelated cord blood transplantation is associated with a smaller risk of life-threatening graft-versus-host disease when compared to marrow transplantation.

Overall, approximately 70-80% of patients who have been treated for non-malignant diseases and 30-40% of patients treated for malignant diseases are surviving. The complications for cord blood transplantation are the same as those of bone marrow transplantation. These include rejection, failure of the graft to function, infection, relapse in transplants for cancer, and side effects related to the preparative regimen before transplant. One potential problem with cord blood transplantation is that engraftment, particularly with platelets, appears to be slower than that associated with marrow transplantation, but usually this is not a clinical problem.

Cord blood transplantation, then, offers the major advantages of ease and safety of collection of a source of stem cells that it otherwise discarded,

instant accessibility from a bank, a lower risk of viral contamination, a reduced risk of severe graft-versus-host disease, and the availability of more appropriate distribution of racial groups compared with unrelated marrow donor banks. Potential legal and ethical questions remain with the use of cord blood stem cells including the issues of informed consent and the need to follow donors to detect possible transmission of genetic or infectious diseases. Currently the National Institutes of Health are funding a study looking at issues of efficient blood banking and the use of these unrelated donor stem cells in a variety of childhood diseases.

Commercial companies have now been formed which offer parents the opportunity to store placental blood exclusively for the use of a member of the family into which the child is born. For fees ranging from \$1250-1500 for the initial storage and \$75-100/year storage, these companies claim that storing cord blood for the exclusive use of a family member serves as "biological insurance" for the child's health. Their brochures claim that "Storing your baby's cord blood is like saving for a rainy day. If your child develops a life-threatening illness that can use stem cells for treatment, the stored cells will be available. They can be a source of treatment for a variety of serious illnesses, including many forms of cancer, blood and immune system disorders, a safeguard against potential illnesses such as Hodgkin's Disease, lymphoma, and leukemia. In the future, as your baby grows older, advances in medical technology are expected to expand the use of cord blood stem cells in the treatment of a broader range of cancer, genetic disorders and other diseases;" that "more than one in ten people may develop one of the severe illnesses that could be treated with cord blood stem cell therapy", and, even if the cord blood is not used for the child for whose birth it was obtained, it "can generally be used for the mother of the child" if she develops "breast or gynecological cancer". Additionally these companies claim that "your child's banked cord blood provides a registered genetic identification source in cases of children who are lost, kidnapped or run away." The most misleading claim is that "cord blood can be used to treat any cancer or genetic disease that is currently treatable by bone marrow transplantation" and that "the cord blood can always be used for the child from whom it was obtained."

In fact, cord blood can only very rarely be used for the child from whom it was obtained because most diseases can only be successfully treated using stem cells from another individual (allogeneic transplants). It is expected that this will remain the situation for any disease that has a genetic basis (e.g. bone marrow failure, immune deficiency syndromes, sickle cell disease and thalassemia, and other genetic disorders of metabolism). The assumption that cord blood stem cells stored at birth might be useful for a child if a transplant is required to treat leukemia later in life is also very unlikely. In many studies the use of a patient's own cells to treat leukemia (autologous transplants) has not proven any better than conventional therapy. If one examines the indications for allogeneic and autologous stem cell transplant, the only possible indication for storing a child's stem cells for later use might be in the child who develops a malignant solid tumor such as a neuroblastoma or lymphoma, and this also remains debatable (Table I). Storing cord blood is unlikely to make a major impact in this situation because peripheral blood can now be used as a source of stem cells for the treatment of most solid malignant tumors.

Based on the incidence of various diseases, one can estimate the chances of a child developing a disease that may need treatment by stem cell transplantation. This risk is nothing like one in ten, but less than one in over 300. Thus, for every 200,000 babies born every year, approximately 600 would face the risk of developing a cancer or another potentially fatal disease that might eventually need treatment by stem cell transplantation. Two-thirds of these patients, however, would be cured with conventional therapy and would not require a transplant. Of the remaining 200 patients who might require a transplant, 66% would benefit only from an allogeneic transplant, and approximately 70 patients might benefit from an autologous transplant. Thus at most only 0.04% of the cord blood units stored for the baby's exclusive use might actually be used--and this is very likely a gross overestimate.

Alternatively, if the cord blood stem cells were banked for use by any child who needed a stem cell transplant, the chance that those cells would be used productively is much greater. One can make a comparison with current blood banking practices. If blood banks were to store blood only for the exclu-

sive use of the donor or the donor's family, blood transfusion as we now know it, with its enormous potential to save lives, would no longer be available and effective, with obviously catastrophic consequences for many patients. Ideally, if the impact of cord blood transplantation becomes significant, the current national not-for profit blood banks would be the perfect repository for these units just as they are for other blood products.

There are two indications for family-exclusive cord blood storage: (i) in the family with a child already afflicted with a disease in which stem cell transplantation might become indicated or in families where both parents are known to carry the risk of a potentially lethal disease which could be treated by stem cell transplantation, even if they have not yet had an affected child. In these settings plans can be made in advance to store the placental blood, have it tissue typed and other relevant testing performed, and then used appropriately. Most transplant centers working in relationship with a not-for-profit blood bank can arrange this. Hopefully if the impact of cord blood transplantation grows, the national not-for-profit blood banks will be placed in charge of these units, just as they are for other blood products.

In summary, storing cord blood for the exclusive use of a child or family member makes no sense medically and deprives other patients who might benefit from allogeneic cord blood transplantation from having the therapy available. So far there is not a single report of an autologous cord blood transplant using placental blood stored by one of these companies being used to treat a patient. Cord blood stored for the general community use in a not-for-profit bank, however, provides a very viable source of stem cells for stem cell transplantation, and potentially may make a significant impact on developing more accessible and safer stem cell transplantation.

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 Additional references available upon request.
 A portion of the above article was published previously in the *Blood & Marrow Transplant Newsletter*, (1985 Spruce Avenue, Highland Park, IL 60035; (847) 831-1913 [phone]; (847) 831-1943 [fax]; e-mail: help@bmtnews.org; website: http://www.bmtnews.org) Vol. 9, No. 3, October, 1998.

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Glossary:

Allogeneic BMT: Any bone marrow transplant between two individuals, whether they are related or unrelated

Autologous BMT: Marrow is removed from the patient during remission state, stored and then returned to the body after the patient receives high doses of chemotherapy and/or radiation therapy. On occasion, the re-infused marrow is purged of cancer cells before being returned to the patient.

CT: Confirmatory typing: A repeat tissue typing test done as one of the final tests to confirm the compatibility of the donor and patient prior to transplant.

GVHD: Graft versus host disease: A reaction of the transplanted marrow to the patient's body, which can range in severity from a minor skin rash to life threatening disease involving major organs of the body.

HLA: Human leukocyte antigens: The proteins present on the surface of the body's white blood cells which allow the body to recognize self vs. non self. An individual's HLA type is inherited through the genes passed down from their parents. Perfect or near perfect matches reduce the level of GVHD. Includes identification of HLA A,B and DR antigens.

Stem cells or pluripotent cells: Cells which differentiate into the various blood cell lines of the body - lymphocytes, red blood cells, platelets, monocytes, neutrophils, eosinophils and basophils.

Synergistic: Donor marrow for transplant which is provided by monozygotic (identical) twin.

Peripheral blood stem cell transplant: Stem cells collected from the circulating blood stream that are then used as another retrieval source for either an autologous or allogeneic transplant.

Umbilical cord transplant: Stem cells collected from the placenta and umbilical cord, that are stored and later used for either autologous or allogeneic transplant.

Bone Marrow Transplant resources:

Not-for-profit Cord Blood Bank
 New York Blood Center
 c/o Cynthia Claude
 212 - 570-3066
 Call for newly published newsletter

Not-for profit Cord Blood Bank
 Oakland Children's Hospital in California
 c/o Dr. Bert Lubin
 Ph.: 510 - 428-3502

Blood & Marrow Transplant Newsletter
 1985 Spruce Avenue
 Highland Park, IL 60035
 Publishes a newsletter six times per year in addition to a reference book: Bone Marrow Transplants. Provides referrals on BMT-related issues. Services are free, contributions are appreciated.

847-831-1913

National Marrow Donor Program.

3433 Broadway Street Northeast
 Suite 500
 Minneapolis, MN 55413
 1-800-526-7809
 general website: www.marrow.org
 patient/physician website: www.bmtinfo.org
 The NMDP maintains the largest donor registry in the world, containing more than three million volunteer potential donors. The Office of Patient Advocacy has materials and can further explain the preliminary as well as formal search process.

BMT Family Support Network

P.O. Box 845
 Avon, CT 06001
 1-800-826-9376
 Links families involved in bone marrow transplants for telephone support. Provides information and resources. Also serves grieving families. Services are provided by volunteers.

BMTInformation:

A website with information about stem cell transplantation, designed for both patients and physicians
 www.bmtinfo.org

Candlelighters Childhood Cancer Foundation

7910 Woodmont Avenue, Suite 460
 Bethesda MD 20814
 301-657-8401; Fax: 301-718-2686
 info@candlelighters.org
 Resource book: Guide to Bone Marrow Transplants in Children, 1994; free to families of children with cancer and professionals

International Bone Marrow Transplant Registry

414-456-8325
 P.O. Box 26509
 Milwaukee, WI 53226
 Collects and analyzes information and results of bone marrow transplants using data provided by institutions worldwide.

National BMT Link

29209 Northwestern Highway #624
 Southfield, MI 48034
 1-800-546-5268
 A human service agency that assists patients, families, donors and friends with information and emotional support.

Gold Ribbon Campaign

The gold ribbon is the official ribbon of childhood cancer awareness, endorsed by both Candlelighters Childhood Cancer Foundation and the National Childhood Cancer Foundation.

The gold ribbon campaign, to promote childhood cancer awareness began in the summer of 1997 by Gigi Thorsen, as a result of being inspired by the life of her daughter Kelsey who died from leukemia in July 1996.

Gigi felt that there was not enough awareness of childhood cancer in general. Few knew of its frequency, its often brutal and lengthy treatment and average cure rate that had vast room for improvement. Gigi used the internet to promote the ribbon idea, and with the encouragement of parents of children with cancer participating in internet support groups, the campaign caught on quickly! The color gold was chosen because, like our children, it is precious. It also represents the flame of hope and the purity of our children's hearts.

Gold cloth ribbons made their debut September 1997 for Childhood Cancer Awareness Month. The gold ribbon pins were introduced in early 1998. An order form was immediately available online, and between the online orders and word-of-mouth, Gigi alone has distributed over 33,000 pins across the U.S., Canada and several foreign countries.

The gold ribbon pins have not only been purchased by individuals for themselves, family and friends, but also by families raising funds to help defray medical expenses, and Candlelighter groups for fundraising and promoting of childhood cancer awareness.

There are now 3 gold ribbon lapel pins available: the plain ribbon, the ribbon with an angel (honoring the children who have died from cancer) and the ribbon with the Candlelighters logo. **Proceeds from the Candlelighters logo pin will go to Candlelighters National office.**

To order any of the ribbon pins, go to the website <http://www.goldribbonpins.org>, or call Gigi Thorsen at 801-944-4553.

Candlelighters wishes to express our heartfelt appreciation to Gigi for the enormous impact that she has made on childhood cancer awareness!

The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.
Helen Keller

SUBSCRIPTIONS

This newsletter is a free resource publication offered by the Candlelighters Childhood Cancer Foundation. Publication of this edition of *The Quarterly* has been made possible by The American Legion Child Welfare Foundation

To be added to the mailing list :
Return This Form to 3910 Warner St. Kensington MD 20895;
email: info@candlelighters.org
Phone: 301-657-8401 or Fax: 301-962-1579

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Institution, if any

Street

City, State, Zip Code, Foreign Country

Yes! I would like to help children with cancer and those who care for them by making a tax-deductible gift of:

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The Candlelighters Childhood Cancer Foundation is a national 501 © (3) non-profit membership organization whose mission is to educate, support, serve and advocate for families of children with cancer, survivors of childhood cancer and the professionals who care for them.

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@article{Tse2005UmbilicalCB, title={Umbilical cord blood transplantation: a new alternative option.}, author={W. Tse and M. Laughlin}, journal={Hematology. American Society of Hematology. Education Program}, year={2005}, pages={. Umbilical cord blood transplantation is a graft source for patients who do not have a matched donor in their family or in the unrelated registry. It is particularly difficult for Black, Hispanic, and White patients of non-Western European background to find fully matched adult volunteer donors. An estimated 700,000 umbilical cord blood units have been donated for public use, and over 40,000 umbilical cord blood transplantations have been performed. Over 25,000 patients have been cured with this approach. READ ALL. Cord blood transplantation, then, offers the major advantages of ease and safety of collection of a source of stem cells that it otherwise discarded, instant accessibility from a bank, a lower risk of viral contamination, a reduced risk of severe graft-versus-host disease, and the availability of more appropriate distribution of racial groups compared with unrelated marrow donor banks. Cord blood transplants can be a good choice for people without a matched donor. This is particularly the case for people who need conventional transplants. Learn more about Memorial Sloan Kettering's research on cord blood transplantation. Donor Lymphocyte Infusions (DLI). For people with certain types of cancer that has come back after a stem cell transplant, doctors may slowly give them more T cells from the original donor. Outcome of cord-blood transplantation from related and unrelated donors. *New England Journal of Medicine*, 337, 373-381. 4. Harris, D. T., Badowski, M., Ahmad, N., & Gaballa, M. (2008). The potential of cord blood stem cells for use in regenerative medicine. *Cell Transplant*, 13, 113-122. 54. Chen, R., & Ende, N. (2000). Intraspinous transplantation of CD34+ human umbilical cord blood cells after spinal cord hemisection injury improves functional recovery in adult rats. *Cell Transplant*, 13, 113-122. 54. Chen, R., & Ende, N. (2000).