

neuro•fibroma•tosis

Colorado Chapter
PO Box 101357
Denver, Colorado 80250-1357
Phone: 303.460.8313
Fax: 303.460.1421

Colorado CTF Contacts

President:
Mark Ebel,
mark.ebel@alumni.duke.edu,
303-734-9942

Treasurer:
Hilarie Watters, hilathome@msn.com,
303-422-1361

Secretary:
Andrea Dukakis, adukakis@viawest.net,
303-394-0038

Outreach:
Jane Cahn, janecdenver@aol.com,
303-322-4194

Colorado Springs:
Carol Ferrara, 719-596-5182
Dana Stanley,
danaapril@aol.com, 719-574-1754

Grand Junction:
Cathy Green,
cg79@aol.com, 970-257-1260

Monte Vista:
Susan Carroll,
sunsetdreams_03@hotmail.com,
719-852-3114

Colorado NF Information Line:
303-460-8313

NF Clinic at The Children's Hospital:
303-861-6395

Adult Genetics Clinic
at University Hospital:
303-372-2929

Children's Tumor Foundation:
www.ctf.org, 800-323-7938

PGD (preimplantation genetic diagnosis) in NF

By Susan Conradi Toomey, M.S.
Genetic Counselor

In reproductive centers the world over, a new procedure has allowed couples at risk of having a child with neurofibromatosis the ability to screen an embryo for the defective NF gene, prior to a pregnancy being achieved. Preimplantation genetic diagnosis, known as PGD, is a genetic screen used in conjunction with in vitro fertilization (IVF).

Prenatal diagnosis (amniocentesis or CVS) has been available for decades allowing at-risk couples to diagnose neurofibromatosis in an ongoing pregnancy.

If a fetus was found to have NF, the couple faced the agonizing decision to continue or terminate the pregnancy. PGD is a valid alternative for couples wishing to avoid decisions about pregnancy termination by providing the opportunity to know that any pregnancy achieved should be unaffected, thus negating the ethical-moral problems associated with pregnancy termination.

Just as with prenatal testing, mutation or linkage analysis must be performed in advance and be informative.

Continued on Page 3, Column 1

NF Issues In The Workplace

Saturday, November 19th
1 to 3 PM

Denver Museum of Nature & Science
2100 Colorado Boulevard
Denver

- Interested in sharing NF related workplace experiences?
- Open to learning how others have dealt with appearance differences, health insurance concerns, Social Security, and disability needs?
- Willing to contribute as a panel participant or have a speaker to suggest?
- Have unique ideas about workplace issues you would like to see presented?

Save the date on your calendar.

Continued on Page 2, Column 1

Tee For Two

Charity
Golf Tournament
Four Person Scramble



Monday, September 26, 2005

Fox Hill Country Club
1400 East Highway 119
Longmont, Colorado 80502
303-772-0246
www.foxhillcc.com

WE NEED YOUR HELP

The Children's Tumor Foundation and The Christopher Saathoff Foundation are teaming up to bring a business-oriented golf event to Colorado. These are two very deserving causes that need your help. What better way to help two great non-profits than to support this golf tournament.

Continued on Page 7, Column 1

The President's Letter

By Mark Ebel, CTF Colorado Chapter President

The four-year anniversary of September 11 is approaching and the world continues to be a dangerous place. Americans continue to lose their lives in Iraq and Afghanistan. The recent terrorist bombings in London remind us that we are still vulnerable to future attacks here as well. For some of us, though, NF presents a more immediate, more personal and scarier scenario than another terrorist attack.

The Colorado Chapter of the CTF has a number of families that are going through difficult times dealing with complications associated with NF. Some are dealing with the early onset of puberty, others with significant learning disabilities or behavioral issues, and still others with scoliosis, optic gliomas, complicated plexiform tumors, and even NF-related cancer. Having seen how some of these families have dealt with these challenges, I am truly inspired by their strength and courage, and by the thankful and optimistic attitudes that they maintain in the face of adversity.

I also think about how valuable their stories could be to others who might be going through similar situations or feeling similar emotions. We frequently include

a story about a family's experience with NF in our newsletter. However, there are many stories that only get told in small support groups or during one-on-one conversations and there are others that never get told at all. I believe there is a need to compile some of our stories into a booklet, which we could make available to our members for a small fee.

The Texas Neurofibromatosis Foundation recently published a book called *14 Stories: A Guide for Patients and Families Living with Neurofibromatosis*. While their book includes medical information and resource contacts, my vision for our booklet involves a collection of purely personal stories. If you would be willing to share your story, please contact me or any of our board members to arrange for an interview. If you wish, your story can be included anonymously. Please consider contributing to this valuable effort!

In the meantime, if you would like to order a copy of the Texas Neurofibromatosis Foundation book, you can contact them at 6555 Sierra Drive, Irving, TX 75039, or call 1-800-942-8476 or 972-868-7940.

Family Fun

Popsicles On The Playground

Sunday, September 11th, 2 to 4 PM

Please join us for a fun family get-together on the campus of Colorado Academy. We will plan age-appropriate games for children ages 3 to 12 to help them get to know each other. Young adults ages 13 to 18 would be ideal volunteers to help run games. To RSVP or volunteer to help, please contact Catherine Laskey at 303-914-2571 or ilaskey@peakpeak.com.

Colorado Academy is located at 3800 South Pierce Street in Denver, 80235
Directions: Just south of the Hampden (Highway 285) frontage road between Sheridan and Wadsworth Boulevards. On campus, veer left at the fork for the playground.

NF Issues In The Workplace

Continued From Page 1

Additional details will follow. We welcome your suggestions! Please contact:

**Tom Hattenburg, 720-870-9248, tomh711@comcast.net
or Rod Slaght, 303-278-9019, rods2002@msn.com**

Quarterly Donor Acknowledgements

AIG Matching Grants Program
Albertson's Community Partners Program

Marjorie Anderson

Merle Brouwer

Gregory Button

David Casler via United Way

Andrew Clauss

Community Health Charities of Colorado

Daniel Comstock

Friends and Family of Davis Ebel

Pamela Grange

In Memory of R. Stephen Green

John Hereford

Stephan Hodge

Brendan Keenan via United Way

Erin Laffrenzen

Thomas Lough via United Way

L. Lee McDowell

Oppenheimer Funds, Inc.

Katherine Piffer

John Quinette

Gail Schoettler

Richard Simons

Thomas Smith

John B. Speight Foundation

Kelli Suarez via United Way

Sun Microsystems Foundation
Matching Gift Program

Laurene Thompson

United Way of Larimer County

David Van Tassel

Mark and Hilarie Watters

Ray and Tricia Whyntott

When sending your contribution to Colorado CTF or directly to the CTF main offices in New York, please designate "Colorado CTF" as the Payee. Thank You!

PGD (preimplantation genetic diagnosis) in NF

Continued From Page 1

Direct Mutation Analysis will detect up to 95% of mutations responsible for NF1 and up to 60% of mutations in NF2. For both NF1 and NF2, linkage analysis can be performed with greater than 95% accuracy in families with two or more affected individuals. Once mutation or linkage testing is complete, PGD can be offered.

Couples who choose PGD undergo an in vitro fertilization (IVF) cycle which entails removing eggs from the woman's body and fertilizing them with the man's sperm in a laboratory setting. In an incubator, the fertilized eggs develop into embryos. At approximately the 8-cell stage, a single cell is biopsied from each embryo and sent for analysis while the developing embryo remains in the incubator to continue to grow. The cells removed from each individual embryo are sent to a specialized laboratory and quickly analyzed by genetic testing using PCR-based DNA amplification. Those embryos considered to be unaffected are

selected for transfer into the woman's uterus while the embryos considered to be affected are discarded.

Typically, the accuracy of PGD is between 90-98% depending upon the exact laboratory methods utilized. PGD does not replace the need for prenatal testing, as PGD is a research-based test with limitations in accuracy. It is best to think of PGD as a screening tool which greatly reduces the risk of an affected pregnancy occurring. Prenatal testing is still recommended, as a way to confirm the results of PGD.

Like all genetic screening, PGD has risks and limitations. When mutation or linkage analysis is uninformative, PGD (and prenatal diagnosis) can not be offered. An IVF cycle with PGD can be rather expensive and insurance companies rarely cover the cost of IVF. Some patients, however, have been successful in obtaining insurance coverage for the PGD portion of the cycle. PGD can not

predict the potential severity of NF in the embryo and, at this time, can not rule out additional genetic defects in the embryo. There is a 1% risk of accidental damage to an embryo during the biopsy; and if damaged, the embryo (even if unaffected) would typically stop growing and would not be suitable for transfer into the uterus. Recent reports have revealed a potential link between IVF procedures and a slight increased risk for certain birth defects. And finally, for some couples, ethical concerns may still arise when discarding affected embryos.

In the last several years, PGD has been successfully implemented in families with both NF1 and NF2, resulting in the birth of healthy unaffected babies. If you are interested in discovering whether PGD is an option, ask your OB/GYN or NF Clinic to refer you to an IVF center that offers PGD. Many IVF/PGD centers have trained genetic professionals who can counsel patients regarding the risks, benefits, and limitations of PGD.

Albertsons Community Partners Join Today to Help The CTF

Cards Are Accepted At Albertsons, Sav*on Drugs, And Osco Drug Stores

To join online: Go to www.albertsons.com. Click on "In The Community" then click on the "Community Partners" logo link. Once you log in, click on "Sign me up". Our Community Partners ID# is 49000119348.

To join by mail: Fill out the following and mail to:
Community Partner Program Headquarters, PO Box 193,
Bethel Park, PA 15102-0193.

Children's Tumor Foundation, Colorado Chapter

School/Organization Name

49000119348

Community partner ID#

Your Preferred Savings Card #

Your First Name

Last Name

Phone # (for verification purposes, if necessary)

Gratitude and Transitions

By Jane Cahn

The time has come again for the job of newsletter editor to be picked up by someone else in our Chapter. For the last two years, Kathleen Petersen has faithfully served in this volunteer capacity with amazing humor and style. Seldom was a newsletter completed without light-hearted laughter and deep reflection. Thanks Kathleen for making the last two years go so well.

In addition to Kathleen's departure, we are also saying farewell to Amaranth Graphic Design. Amaranth has graciously offered their services and understanding for over fifteen years to our Chapter. Their creativity and professionalism have never wavered throughout that time. Thank-you to Judy and Iz for their reliability and concern.

Thanks also to Bruce Nall, Chapter member and commercial photographer for his work to produce the Summer mailer, Tee For Two information sheet and other items for the Chapter.

Bruce will also be involved in producing the monthly CTF Colorado Chapter newsletters. Contact Bruce at bnall@selectimage.net or PO Box 620579, Littleton CO 80162-0579.



Mark Watters

Mark Watters Receives Law Enforcement Award

Our Chapter has had the pleasure of knowing Mark Watters as the co-organizer of our annual picnic, the husband of Hilarie, our treasurer, and the father of 6 year old Paul who lives with NF, 9 year old Clarise, and 12 year old Moira. He is also the police officer who has generously taken several of our children on police ride-alongs for community service projects. Recently Mark was honored with the National Law Enforcement Appreciation Week Employee of the Year for the City of Westminster. This week commemorates officers killed in the line of duty and honors all law enforcement personnel who serve their communities.

Five years ago the Tri-City Baptist Church of Westminster initiated the award to show support and appreciation for the efforts of excellence in community law enforcement. Mark was nominated and selected by fellow officers to receive this honor. As Chapter members, we are proud to know Mark and to see him recognized formally for being a model of integrity both professionally and personally.

Atta-boy Bob! Bob Skold Is Running Again

This fall Bob will be running for NF in the November 7th New York Marathon. Over the years Bob, who has NF2, has raised thousands of dollars for NF research by running in events across the country.

Please let him hear your words of encouragement and appreciation at bskoldjr@aol.com or:

Bob Skold
11967 E. Lake Circle
Greenwood Village, CO 80110

Congratulations to Special Olympics Participants!



April Stanley



Matthew White

Congratulations to Recent Graduates!



Erin Nakamura graduated from Mach-beuf High School in Denver



Josh Baron graduated from Pikes Peak Community College, is working at King Soopers and attending the University of Colorado at Colorado Springs.



Stephanie Friesen graduated from South High School in Denver and is attending Hesston College in Hesston, Kansas

Meet Mckaila Steffes



Mckaila Steffes (right) and Wyatt

Some children just seem to have a knack for doing lots of things well, being really smart and knowing how to have fun. You can say all of those things about 9 year old Mckaila Steffes who mastered the fine art of cursive writing this year, loves swimming, softball, ice-skating, dancing, chocolate, reading, the color lime green and making people laugh. This spring Mckaila's schedule was diverted following surgery and her diagnosis of a malignant peripheral nerve sheath tumor. Six weeks of radiation followed and six months of chemotherapy are now in progress.

Parents Dan and Sandie have been a part of our Chapter since Mckaila was very young. They coordinated the 2001 NF Symposium and have annually organized the St. Patrick's Day Parade for us. Mckaila and family are surrounded by the love of family and friends at work, school and church. They are very grateful for the expressions of support from the Colorado Chapter Board and others who know them. All words of encouragement are welcome. We invite you to visit Mckaila and leave her a message at: www.caringbridge.org/co/mckaila

If you or someone in your family with NF is experiencing a current challenge with NF and would like to have contact from someone in the Chapter, please contact Jane Cahn at 303-322-4194 or janeccdenver@aol.com.

Remembering Grace

By Jane Cahn

Grief can sometimes feel like an elephant sitting on your chest. The elephant isn't always there but the memories of Grace for Judy, John and Bradley Becerra are seldom far from their hearts. Grace had a very complicated journey with NF but she still managed to light up a room with her smile as she gave and received tremendous amounts of love daily.

The Becerra family was living in Arizona when they adopted Grace. She was first diagnosed with NF at three months of age but received most of her care at Denver's Children's Hospital when her family moved to Denver in late 2001. It was in Denver that the Becerra's learned that only six children in North America had the adrenal cortical carcinoma that Grace had at the time of her death. Grace also had many other NF tumors throughout her body.

But Grace's spirit is present also. Grace was a comforter. She knew how to reassure Judy and John even when they were making one of their many trips for her to be admitted to Children's. Grace was also a boss in constant search of someone or something to order around. She became quite authoritarian with the animals demanding that they "go outside" or "hush." She was a comedian who could invariably turn a tense moment into laughter and she performed right along with The Wiggles who were her favorite children's performance artists. Even at three she knew how to live life to the fullest and she fought the cancer like she did other things in her life she didn't like – if she liked you, you knew it and if she didn't (usually temporarily), you knew where you stood. She would be angry after getting a shot but forgiving moments later.

Grieving a child's death can take a strong toll on a family. Knowing others who have had the experience through Compassionate Friends and Hospice has been helpful to the Becerras. Talking with others who understand the pain of a parent meets a great need, especially for a father who usually makes things better but can't. Grace didn't survive to take the dreamed of Make-A-Wish trip but Judy and John knew that Bradley had been looking forward to the trip also and the family followed through with the plan after Grace's death.

Life continues after the loss of a child but the form of life is altered and the new meanings that come take time. Faith has taken a shift but it is still present for the Becerras. The memories are always close at hand. For Bradley, his Valentine card to his sister this year captured the part of life with Grace that will live on: "I love you. You're the best sister in the whole world. You don't have to give me a present because you give me a present every day – it's my sister Grace."



Grace Becerra
March 22, 2001 – February 22, 2005

Helping Your Child Cope with Neurofibromatosis

A consolidation of an article by Helen Hand, PhD, University of Denver

Neurofibromatosis (NF) is difficult to explain because it is a complex and variable disorder with no predictable course, no certain prognosis, and can vary in severity.

Parents feel a sense of loss and fear when a child is born with a health issue like NF. Keep your own fears in check and you will keep optimism alive in your child. Before approaching your child affected by NF, consider your own feelings as well as your child's age and individual ability to understand a variety of concepts.

You may assess your own grief and fears using the classic stages of grief outlined by psychologist Elizabeth Kubler-Ross and modified for NF below. These stages do not represent a step-by-step process having a tidy ending. Instead, you will move fluidly back and forth between these phases from time to time.

Stage I: DENIAL

- "He just has some birthmarks, otherwise he's fine."
- "There cannot be anything wrong, she looks and acts perfectly healthy."

Stage II: ANGER

- "What have we done to deserve this?"
- "Why my child?"

Stage III: BARGAINING

- Promises to God like, "I'll quit smoking if you make this go away."
- "I'll be OK if the NF amounts to just café-au-lait spots and learning disabilities."

Stage IV: DEPRESSION

- "What will become of my child?"
- "I've failed as a parent."

Stage V: ACCEPTANCE

- "My son may have NF, but he's like any other child."
- "I accept that my daughter has NF. Now, what can I do to help her and others?"

Your child will pass through the following developmental stages. These stages are not rigid (some children develop more quickly in one area and more slowly in another), but particular explanations will make the most sense at certain ages. You are the best judge of your child's development and ability to understand aspects of NF.

If your child receives professional treatment, she must understand that she is an important member of her treatment team. If she understands her role, she will become independent and self-sufficient in handling events like doctor visits, exams and special education conferences.

Here are some general developmental characteristics of certain ages:

Prior to Age Two

Before age two, children begin to develop language skills and to understand the world around them. Explanations should be reserved for the next stage.

Two to Four Years of Age

Your preschooler doesn't yet understand cause and effect in his relationships. However, he can separate his thoughts from his actions. His thoughts are linked to the concrete, observable and tangible. He cannot grasp the idea that NF is caused by an underlying genetic disorder; nor can he grasp more than one idea, or symptom, at a time. Therefore deal with one issue at a time and explain it in concrete terms.

Use the term neurofibromatosis and NF in conjunction with specific symptoms and introduce him to the NF community. Clearly distinguish between the disorder and him; he is never the problem. Include positive comments about his strengths (i.e. great attitude, sunny smile) and assets (i.e. loving family, good health care).

Connect rituals with frequent medical appointments (i.e. choice of clothing for visit, snack or playtime after appointment, choice of route to the office). He will feel more in control over his care.

Four to Six Years of Age

At this level your child will begin to understand cause and effect. You may now explain underlying causes of NF and external manifestations. You will have more success if you tackle one NF-related subject at a time, though. Ask her to repeat your explanations back to you.

She may express anger about having NF at this stage. Allow the feelings, but remind her that she is separate from the disorder. Explain that life is often imperfect and unpredictable, and some people have more to deal with than others.

Role-play with her to train her to explain the disorder to others in a variety of social situations. She will not have the answers she needs at her disposal unless she is prepared. Model answers in conversations and social situations where she is present. You are preparing her to think fast on her feet with peers and teachers and maintain dignity with word tools. If symptoms are apparent, she needs to be able to say things like, "I have NF...it's not contagious. I am used to it and you will get used to it too."

Six to Ten years of Age

By this stage, your child appreciates complexity. Comparison with others begins. As he thinks of the future, he may ask,

Helping Your Child Cope with Neurofibromatosis

“If this is a struggle now, what about the future?” Discuss his struggles with comparisons and the unpredictable.

Discussions of the genetic aspects of NF may include “the body has a map or plan inside that tells your hair and eyes what color to be. That plan can sometimes create the brown spots and bumps you see on your skin.” Elaborate on specific questions, but don’t go beyond his understanding.

Emphasize that you and your child are part of a team of medical and educational professionals and others who know it’s important to observe, learn about and deal with current symptoms. Stick to today’s events and talk about them in real, present and concrete terms; but confirm that he will have your support and understanding in the future.

Adolescence

Your adolescent will have more serious concerns. Relationships with the opposite sex and developing a distinct self-identity become major issues. As a result, family dynamics are more

complex. If your teen makes a mistake or has mixed feelings about an issue, she may blame you for the negative parts. Often she will set up a fight with you rather than face the problem or mistake for herself. By focusing outside herself, she defends against painful anxiety.

Rather than simply absorbing the blame, you can gently return the struggle to your child. For example, if your child resists treatment or therapy, you could say “You are angry because I am making you go to the doctor again. Please consider that you may be angry because you have NF. It is difficult to deal with it all the time and you have reasons for anger.”

Staying Positive

Optimism is not sugar coating problems. It is understanding that there is always something you can do to better a situation – a support group, latest research advances, focus on what is going well in your child’s life. Show your child there is always some way to cope effectively with any situation. Above all, you can give your child hope.

Tee For Two Charity Golf Tournament

Continued From Page 1

AGENDA

- 11:00 AM Registration and Range Practice, Lunch
- 12:30 PM Shotgun Start
- 5:30 PM Reception & Silent Auction
- 6:30 PM Awards Dinner

ENTRY FEES

\$200 – Individual, \$750 – Team

Includes player gift, green fees, cart, practice balls, prizes, box lunch and dinner

Dinner tickets are available for \$50

SPONSORSHIPS AVAILABLE

Please contact Jerry Hunter at 303-926-1644 if you and/or your corporation would like to become a sponsor of this golf tournament.

SILENT AUCTION

Don’t miss your chance to bid

Current Auction Items:

- Condo in Mexico for a week.
- Weekend for two in Scottsdale, Arizona.
- Football autographed by John Elway.
- Weekend stay for two at the Inverness Hotel.
- Weekend stay at the Westin Westminster.
- Omni Interlocken Resort overnight stay, brunch and golf for two.

If you have an auction item to donate, please contact Stephanie at 303-931-4659 or 303-665-3474.

REGISTRATION

Register online at www.tee4two.org or Mail Registration and Payment to:

Tee for Two
1603 Walker Street
Erie, Colorado 80516

Need More Info? Call 303-926-1644

THANKS TO GINNY’S KIDS!

Ginny’s Kids is a Colorado non-profit organization committed to assisting children with life-threatening and chronic conditions; they continue to be a resource to the Colorado Chapter. For over five years they have been helping children with NF take trips, go to camp and visit Elitch Gardens in Denver. Their support reminds us all that we are all in this experience of living together. We are especially grateful to **Homer Anderson** of Arvada for his on-going efforts.



NF Clinic Coordinator Kristina with her new son. 8 lb. 4 oz., 21 inch Ethan Robert was born on Sunday, July 10th. Congratulations to new parents Kristina and Carl Kocsis.

Children's Tumor Foundation
Colorado Chapter
PO Box 101357
Denver, CO 80250-1357

NON-PROFIT ORG.
U.S. Postage
PAID
Denver, CO
Permit No. 5323

RETURN SERVICE REQUESTED

EVENT CALENDAR

Family Fun — Popsicles On The Playground — Sunday, September 11th, 2 to 4 PM — Page 2

Tee For Two — Charity Golf Tournament — Monday, September 26, 2005, 11:30 AM — Page 1

NF Issues In The Workplace — Saturday, November 19th from 1 to 3 PM — Page 1

The deadline for material to be included in the winter newsletter is October 10th

Please send material to Bruce Nall, bnall@selectimage.net or PO Box 620579, Littleton CO 80162-0579

ATTENTION

Children And Teens With NF & Their Parents!

Drew Bradlyn, Ph.D., of the Health Behavior Research Center at West Virginia University is conducting research to better understand the impact of NF on the lives of children and teens. Participants (children and teens, age 8 to 17, and their parents) will receive \$10.00 for completing a questionnaire and returning it by mail.

To learn more about this study, call Dr. Drew Bradlyn or Erin Wilt at 304-293-6218 or e-mail abradlyn@hsc.wvu.edu or ewilt@hsc.wvu.edu.