BCCNS Life Support Network

Fall 2005

Quarterly Advocate

Family Support

Please keep these family members close to your heart in thought, word, deed and supplication.

Marj Campbell & Family
William Connolly
Oliver Dean
Stephen Douglas
Jim Finkbiner
Jon Johnson
Susan Johnson
Kayla Marine
Dustin Miller
Troy Miller
Anne Myers
Pamela Nickell
Brandon Pearsell
The Pelman Family
The Phillips Family
Frankie Roller
Mary Lou Smith
Debra Sweet
Teresa Sweet
Jennifer Werkmeister

Elderly Man

Submitted by: Patricia Pearsell

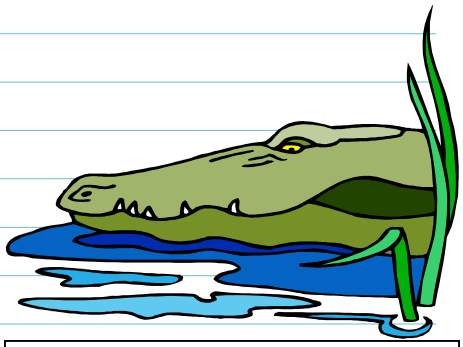
An elderly man in Florida had owned a large farm for several years. He had a large pond in the back, fixed up nice; picnic tables, horseshoe courts, and some apple and peach trees. The pond was properly shaped and fixed up for swimming when it was built.

One evening the old farmer decided to go down to the pond, as he hadn't been there for awhile, and look it over. He grabbed a five-gallon pail to bring back some fruit. As he neared the pond, he heard voices shouting and laughing with glee. As he came closer he saw it was a bunch of young women skinny-dipping in his pond. He made the women aware of his presence and they all went to the deep end.

One of the women shouted at him, "We're not coming out until you leave!"

The old man frowned, " I didn't come down here to watch you ladies swim naked or make you get out of the pond naked."

Holding the bucket up he said, "I'm here to feed the alligator!"



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Extra, Extra read all about it!

The following people are celebrating birthdays in the month of:

September-Bryant Bradley, Allicyn Allen, Christy Sweet, Bridget Koenig, Stu Needel

October-Lance Davies, Abby Michalowski, Nina Bradley, Rocki Finkbiner, Jim Finkbiner, Michael Michalowski, Timothy Pelman

November– Emilio Valdez, Teresa Sweet, Joan Boes, Brittany Black, Sarah Neimeister

Family Member, Christen Gullatt , along with close friend and fellow teacher, Brooke Kasbaum have created a new business. **Ashlee Cole Creations** creates personalized poems, invitations, announcements, and letters to family, friends and co-workers. These talented writers have also pledged to send a portion of their profits to the BCCNS Life Support Network. For more information on their company, visit their website at www. Ashleecolecreations.com. Below is a sample of their work:

Father of the Bride

The soot stains are covered
No sign of the flame
What was I thinking
My pipe to blame

The creek has been cleaned
The chairs are in place
The guests have arrived
Smiles light their face

The hedges are groomed
Her mother is seated
A goober salesman looms
And my tux has been pleated

All in all it's a beautiful day
My daughter standing by my side
The time has come to give her away
For I am the Father of the Bride

Welcome New Families

BCCNS Life Support Network extends a warm welcome to the following families:

Brant Family in Ohio
Capuano Family in Delaware
Hendrick Family in Tennessee
Lamm Family in Illinois
McKay Family in Indiana
Nelson Family in Ohio
Porteus Family in New York
Turley Family in Oklahoma

First Person Story– by Marjorie Campbell, Tennesee

The following was originally posted on the patient forum in 2001 by a favorite family member, Marj Campbell. Since so much has happened in her life since then, she has updated the original for us. The post topic, originated by Bill Costa, challenged members to list the Best and Worst aspects of living with BCCNS:

WORST experiences: I have had several. They are:

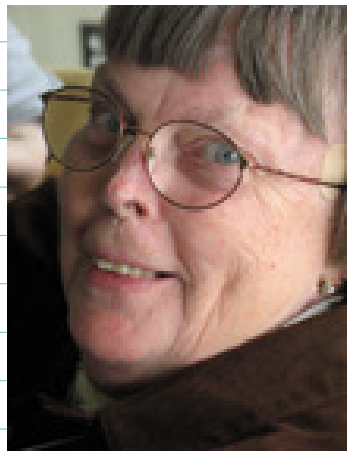
1. Surgeries for removal of 11 jaw cysts and impacted molars.
2. Being told I had a "rare, unknown, probably incurable disease".
3. The embarrassment I felt due to people giving me strange looks, asking about bumps or sores, prolonged bandaging, and refusing to hand me change from a purchase (After I reached for my money, palm up with palmar pits showing, some cashiers would look at my hand and lay my money on the counter).
4. Trying to go it alone and not show the internal distress.
5. Not knowing if my only child had the syndrome.
6. Removal of 1,000+ basal cell carcinomas with surgeries ongoing. Chief among those were seven massive MOHS surgeries, ranging in duration from 61/2 hours to 12 1/2 hours. Long recovery periods when necessary because it was my choice to let the wounds granulate rather than being repaired. I wore my NIKE caps for three years because my head is not "uniform" and wigs didn't fit.
7. The most horrendous day of MOHS surgery was February 7, 2005, when most of my nose tissue was removed. After so many years of surgery, my system processes anesthetic too fast; so pain medication flowed continuously two hours into the surgery and did little to relieve the pain.

BEST experiences: I also have several. They are:

1. After three days of continual testing at the National Cancer Institute in August 1985, I received a confirmed diagnosis and an explanation of the syndrome, which included the following: NBCCS was a genetic disorder and was not life threatening, but would require a lifetime of medical care.
2. Being advised Donald (my son) did not have the syndrome.
3. The realization that I needed, and could get, support from other NBCCS patients. I found the NBCCS Patient Advocate web site with so much information and so many links to other BCCNS websites. I became a member of the BCCNS Life Support Network Patient Forum with so many members that are concerned, friendly, knowledgeable, caring, sharing, and eager to give comfort via cyberspace. I also became an active member in the BCCNS Sunday Night Chat Room.
4. Attending the BCCNS LSN Annual Retreats (They are wonderful experiences!!) and actually meeting people with BCCNS, outside of my immediate family. Developing an "extended family" and many friendships with people that understand what life with BCCNS is all about.
5. Learning and accepting the fact that "I do not walk alone."
6. Assisting with fundraisers for the BCCNS Life Support Network's Annual Retreats. For instance, even though I never considered myself a public speaker, and often avoided speaking requests until this past year, I am now comfortable giving presentations regarding BCCNS and requesting donations to help offset the cost of the BCCNS Life Support Network Retreats.
7. I now know that if other people have a problem with the way I look, it is their problem—not mine, largely due to the support I have received from my "extended family". For instance, after the reconstruction of my nose in February 15, 2005, I did get a lot of stares due to the extensive bandaging on my nose/face. I am now able to withstand or ignore the stares and secretive peeks.

To All: Take care, and keep smiling my friends. Marj

Editor's Note: Thanks for sharing Marj! Maybe you would like to take Bill's challenge and create your own "Best & Worst" list? If you would like to share your list, send it to the BCCNS LSN office. We'd love to hear from you!



Challenge Fundraising Update

We received a very generous matching grant from *The Eric and Jane Nord Foundation*. Any donation that we receive between now and October 31, 2005 will be matched by them up to **$40,000**. To date, we have received **$17,307**. Please help us to take full advantage of this opportunity by giving generously.

The Pearsell family in Canada recently held a garage sale and donated the proceeds to BCCNS Life Support Network. Not only did we receive **$222** from them but it will be matched by the Nord Foundation.

Cindy Shelley wrote a letter to Jana Stanfield and the Caterpillar

Society requesting help with our grant and received a pledge of **$1000**. Every contribution helps to meet the challenge.

Do You have a Social Worker on Your Medical Team?

By Rebecca A. Dougherty, MSW LCSW Saint Louis University Cancer Center

'I don't need one of those."

Well, exactly what is one of those? Yes, a social worker, not a hand out or someone who will monitor you as a parent. How about a trained professional who possesses clinical skills that can foster your understanding of your child's chronic illness, as well as assist you in obtaining educational, community or financial resources.

Believe it or not, social workers are just as varied as doctors and we specialize just as your doctors do. Now, you certainly would not seek out professional advice on BCCNS from a social worker who works in a nursing home, just as you would not take your child to a doctor who specializes in geriatrics. You would look to the specialty training of a medical social worker. Most of these social workers possess a master's degree (6+ yrs. of college training) and continue on for additional training. Many of them possess a license to practice and are able to provide supportive counseling or individual/family therapy. Medical social workers are found in hospitals, physicians' offices, pediatric care centers and cancer centers. Most academic, medical institutions have social workers in every department.

Medical social workers can then specialize even further into pediatrics and or/cancer. This specialty receives further training in chronic illness and disease. Many of these social workers act as facilitators with children and families during the most critical times of your life. They receive training in crisis intervention, impact of a chronic illness, cultural diversity, ethics, advocacy, stress management, care planning, family systems, and individual/family counseling. These skills can come in handy when you feel overwhelmed with your situation, concerned about your child, not sure how to talk with your child or prepare them for the next step, confused about the care plan or would like to look into obtaining additional support or education.

Medical social workers have access to databases, community resources, educational material and more importantly, can take the time to sit and **LISTEN** to you. Sometimes, when you feel overwhelmed, it can be helpful to take all of your anxiety provoking thoughts and get them out. Social workers can take those thoughts and work with you to prioritize what has the most meaning, and begin an action plan with you to improve your quality of life. The more control you can take away from this chronic illness, the less anxiety and stress you will experience.

Usually, social workers are a part of the medical team, in those cases; you would be followed by one social worker. If your child is seen in a doctor's office and is then hospitalized, you may encounter a social worker in each place. Social workers in the hospitals tend to focus more on the discharge planning process and ensuring that as much support is provided to you and your child when they are ready to return home; while social workers in the outpatient setting can focus on long term, quality of life needs, supportive counseling, adjustment to illness, and access to resources.

As a medical social worker, I can tell you that the 3 top reasons I see patients/families are for: caregiver stress, advocacy (with the medical team or to obtain resources) and coping with a chronic illness (that darn illness just gets in the way of everybody's plans). At any point in your care plan, you should have access to a social worker. Sometimes, it may be by just asking your nurse or your physician to speak with one. If you are in a large medical setting, most of the time, there should be a medical social work department where you can ask to consult with someone.

At any point in time you run into barriers in obtaining a medical social worker, please consult with me and I am happy to work with you on locating one. doughera@slu.edu, 314-977-6072.

NETWORK FAMILY BUSINESS

A message from Maria Michalowski and the Board of Trustees of the BCCNS Life Support Network

Since its establishment, the BCCNS Life Support Network (LSN) has endeavored to inform and connect those who are impacted by this disease. To list all of the efforts and accomplishments in these few lines is not possible, but the testimonies of our "family" are available to anyone willing to listen:

"I Am Not Alone"

"I have BCCNS, it doesn't have me"

"Lean On Me"

"Consider Yourself Hugged"

"Keep Smiling"

Each year the reach of the BCCNS LSN has been increased, our Network Family has grown, and members of the medical community have been inspired.

The Trustees remain committed to the By-Laws of the organization, one of which states that no one will be refused services based on their ability to pay. Anyone who contacts the Network will receive comfort, encouragement, literature, referrals and support. The reality is that *most* of those who contact the Network do not contribute financially towards that goal. Donations and fundraising efforts have managed to *barely* support Network activities. Grantwriting efforts as yet have not unearthed the "buried treasure" that was sought. So the Board of Trustees is turning to you, our Network Family, for financial help. Those who contribute regularly to the Network speak volumes:

To New Contacts: "I care, I want to help."

To the Medical Community: "This is important, we need you."

To Foundations & Grantmakers: "This is valuable and worthwhile."

To the BCCNS Life Support Network: "I believe in you."

An explanation of the benefits of being a Contributor is enclosed for your review, but the most valuable benefit of becoming an Annual Contributor is the knowledge that your support directly impacts the next phone call from a panicked parent or concerned doctor. Your Newsletter subscription frees up funds to send a subscription to a new Contact. Each contribution level subsidizes the Network's operating expenses and benefits the entire Network Family.

All contributions made within the next month will be matched by a grant from a generous foundation. In a very real sense, your immediate contribution will be doubled and your regular contributions in the future will continue to strengthen the organization!

Please consider adding your resources to ours. Contribute for yourself, your family, your child…for a special patient, a treasured doctor or nurse, a special friend…in gratitude, in memory of….for the future...

Questions and comments can be directed to :

Maria Michalowski, Trustee & Connection Services Committee Chair

Email: mmski83@hotmail.com

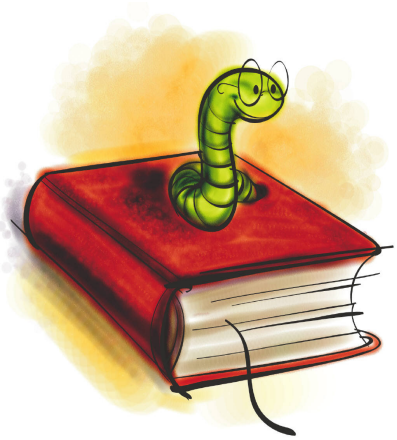
Phone: 724-898-2570

or The BCCNS Network Office .

Did you know? Submitted by Bill Costa

Did you know that a Gorlin Syndrome patient holds the Guinness World Record for Most Operations Endured?

From July 22, 1954 to the end of 1994, Charles Jensen of Chester, South Dakota had 970 operations to remove facial tumors associated with **Basal Cell Naevus Syndrome**, a genetic disorder. The tumors are known to turn malignant and are usually surgically removed soon after appearing. The majority of Jensen's 970 operations were performed by Hymie Gordon, Professor of Medical Genetics, at the Mayo Clinic, Rochester, Minnesota, where Jensen became a well-known visitor who impressed staff with his cheery disposition and willingness to volunteer for training exercises with medical students.



ACRONYM ANTICS!

A great game from the ingenious mind of Bill Costa

Enjoy these acrostics using the acronym BCCNS, and then create your own. Try it with NBCCS, BCNS and even Gorlins. Pick the best ones and send them to the BCCNS Office!

Been **C**ut, **C**auterized "**N** **S**tiched

Buddies **C**hatting, **C**huckling **N**ever **S**topping

Battling **C**ancer **C**ells **N**ever **S**tops

Beware! **C**aution! **C**utup **N**ose **S**tings

Bathingsuits, **C**utoffs, **C**roptops **N**ecessitates **S**unburn

Send us your original acronyms and we will include them in the next issue . . .

University of Pennsylvania Requests Tissue Samples

Submitted by: Dr. Steven Fakharzadeh

July 14, 2005

Dear Kristi,

I am writing to follow up on our previous discussions at the BCCNS colloquium at Saint Louis University and the Society for Investigative Dermatology meeting in May. As you may recall, we talked about the possibility of asking BCCNS patients within the regions surrounding the greater Philadelphia area for basal cell carcinoma tissue samples for use in genetic studies we are performing.

As you know, mutations in the *PTCH* gene cause BCCNS, and complete inactivation of this gene has been implicated in development of basal cell carcinomas. My research involves asking what genetic changes in addition to *PTCH* gene defects are required within skin cells to cause basal cell carcinoma.

To date, we have been studying primarily sporadic basal cell carcinomas (those occurring in patients without BCCNS). Our work is based on performing molecular scans of the entire genome of basal cell carcinoma cells to identify chromosomal alterations that may harbor genes that are important for basal cell carcinoma tumorigenesis. We have detected a number of chromosomal regions we believe to contain genes that contribute to tumor growth, and we are in the process of defining specific basal cell carcinoma genes within these regions.

To expand upon this work, we are asking whether similar genetic changes are seen in basal cell carcinomas from BCCNS patients. If so, this would indicate that other common gene aberrations, in addition to *PTCH* defects, lead to development of basal cell carcinomas in both sporadic and syndromic contexts. Moreover, such genes may represent targets for potential novel, molecular-based therapies for treating or preventing basal cell carcinomas.

In order to proceed with these studies, we need to obtain basal cell carcinoma samples from BCCNS patients. However, I want to minimize any inconvenience to each patient and their dermatologist or primary care physician. Samples for our studies will be obtained at the time of initial biopsy of a suspected basal cell carcinoma or at the time of surgical treatment for a known basal cell carcinoma. I simply ask that a portion of what is removed be given to us for research purposes. No biopsy or surgery will be performed specifically for our research purposes. The only additional procedure I request is a standard blood draw to provide a normal reference sample from the patient to which we compare the basal cell carcinoma. In addition, we will likely perform sequence analysis for the *PTCH* gene, and potentially other genes we identify, using the blood sample.

Clearly, this process will take some degree of coordination between me, each patient, and their dermatologist or primary care physician. I will need to obtain informed consent from patients prior to obtaining samples. I can either send the appropriate forms to patients by mail or FAX and discuss them by phone, or directly meet with patients. In addition, I will need to discuss how to process and receive samples with each patient's physician as well.

I am certain that many of the patients have long-standing relationships with their dermatologists, and by no means do I wish to interfere with this. Nonetheless, I would be more than happy to see BCCNS patients on a consultative basis or for routine care in my clinic at the University of Pennsylvania if desired.

I want to thank you for your help, as well as thank any patients who may wish to contribute samples for our research. Without this support, we would not be able perform our studies aimed at better understanding the molecular basis of basal cell carcinoma.

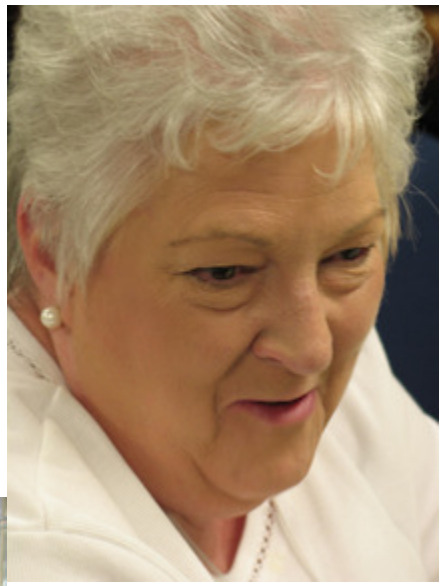
For more information contact, Steven S. Fakharzadeh, MD, PhD at the University Of Pennsylvania Health System, Department of Dermatology, Room 235B, Clinical Research Building, 415 Curie Blvd., Philadelphia, PA 19104, Phone: 215-573-5709, Fax: 215-573-2143, E-Mail: ssf@mail.med.upenn.edu.

The Strength of BCCNS Life Support Network

All photographs on these two pages were done by photographer, Rick Guidotti. Rick generously donated his time to take these wonderful photos. For more information on Rick's work, please visit his website at: : www.positiveexposure.org

Rick took over 600 photos and these represent a few. We tried to show pictures of those who have not previously been spotlighted in the newsletter. More to come . . .

Pamela Allen with her son Devin.



Board President and Trustee, Bryant Bradley.

Daniel Hammond

Nina Bradley

Kathy Cusolito

Janet Humes and her sister Nancy Stroup

John Massimino

Trustee Paul McGoldrick

Our Family Photo Gallery

Pattie Brugger

Daley Marshall

Pamela Nickell

Newlyweds, John & Linda Cox

Danny Neimeister and his mom Tami

Dustin Overman

Molly Marshall

Becky Milligan, also mother of Dustin Overman

Gorlin Kids Page

Jokes & Riddles

1. Johnny's mother had four children. The first was April, the second May, and the third was June. What was the name of her fourth child?
2. What gets wetter the more it dries?
3. What is so fragile even saying it's name can break it?
4. You are driving a bus. Four people get on, three people get off, then eight people get on and ten people get off, then six people get on two more people get off. What color were the bus driver's eye's?
5. Imagine you are sinking in a rowboat surrounded by sharks. How would you survive?
6. Why is it against the law for a man living in North Carolina to be buried in South Carolina?

My Brother's Bug

By Jack Prelutsky from the book, Something BIG Has Been Here

My brother's bug was green and plump,
it did not run, it could not jump,
it had no fur for it to shed,
it slept all night beneath his bed.
My brother's bug had dainty feet,
it did not need a lot to eat,
it did not need a lot to drink,
it did not scream, it did not stink.
It always tried to be polite,
it did not scratch, it did not bite,
the only time it soiled the rug
was when I squashed my brother's bug

G U Q S W O U P R X I Z R D F F R V U I
O B A Q X C V H U R R Y U M K I E B S D
R A Q D B N I O L A L M B H Y T R D G Z
L E G D B I O P S Y A C V B Y N I O P L
I V B N A M K U H E T U L P A L M A R A
N E V U S W E R A U I O L I R P E N A T
Q W E R A T U I D E R M A T O L O G Y O
W C G H L Y U I E L L H G S V B G T E E
R R F G C V B H Y U H N C R E L L Y I O
A Z X C E E R T T B H U L L U I M M O P
Z A S S L E W T T G J I S U R G E O N S
V G T A L I T A L M U T E E W Y U I I K
C F R T S U P P O R T E L M U S I A W F
C G M U T R C A K L E T D X W W Q U S E
F Y O U O L L N V R S E E V T U O M K P
W U H R T O L O Y T T S E E G O U O I M
S H S T S Y C R S E S U N S C R E E N N
E N I E B U I E N U N I O M D A E D Y T
S J U E T U I X O L M U R E R L P O U T
P H O T O D Y N A M I C T H E R A P Y S

GORLIN	NEVUS
BASALCELLS	MOHS
CYSTS	PANOREX
PANOREX	SUPPORT
BIOPSY	SHADE
XRAY	PITS
PALMAR	SURGEON
NEEDLES	TESTS
SUNSCREEN	ORAL
DERMATOLOGY	SKIN
PHOTODYNAMIC THERAPY	

Answers to Jokes & Riddles:
1. Johnny 2. A towel 3. Silence 4. Whatever color eyes you have as you are driving the bus 5. Quit imagining 6. Because he is still living

Ingredient in Curry Appears to Ward Off Skin Cancer

Scientists at the University of Texas' MD Anderson Cancer Center in Houston have found that curcumin, the ingredient that gives curry seasoning its distinctive yellow color, could destroy malignant cells that cause melanoma. Thus far, scientists have only treated human melanoma cells grown in the lab, and next will test curcumin's ability to suppress melanoma cell growth in people. Scientists emphasize that using sunscreen and avoiding excessive exposure to the sun or tanning beds is still the best protection against melanoma. Source: Cancer, the journal of the American Cancer Society.

BCCNS Life Support Network Gains Introduction to St. Jude by Kristi Schmitt Burr

The most proactive, integrative staff and facility for childhood cancer is "phenomenal". "I have toured & the difference in respect for the human journey at St. Jude will forever raise the level of the bar for attainment," notes **Burr**, BCCNS Ex. Dir.

For years, we had hoped to gain some opportunity for introduction to the research being conducted at St. Jude. Initial attempts had not proven fruitful. Then through prayer & action, **Tracy McVicker** wrote a compelling letter to St Jude, resulting in an invitation for BCCNS Ex.Dir, Burr to meet **Tom Curran, PhD**., chair of the Dept. of Developmental Neurobiology, co-leader of the Neurobiology and Brain Tumor Program at St. Jude facilities. Mtgs. with **Dr. Curran**; **Dr. Amar Gajjar,** Dir. of Neuro-Oncology; **Dr. Larry Kun,** Chair of Radiologic Sciences; **Dr. Malika Tuli**, Dermatology; and **Dr. Eniko Pivnick**, Genetics, LeBonheur Children's Medical Center.

Life Support Bd. Mem.**Carl Hans Muller** attended & helped spark lively discussion in the exchange of concepts, challenges and hope for future collaboration between BCCNS LSN & St. Jude staff. In 2006, a study concerning novel treatment for brain tumors with leading pharmaceutical company **Genentech** may lead to an opportunity for participation with Drs **Curran & Gajjar.**

An article, about their novel approach to eradication of medulloblastoma in mice by blocking the function of a molecule called Smoothened (Smo), which may inhibit cell proliferation and lead to the death of certain tumor cells, can be found in the Sept. issue of *Cancer Cell. M*ice in the study were bred to lack one of the two copies of a gene called Patched 1 (Ptc1). Gorlin patients in some cases have a common bond.

ALSAC, the American Lebanese Syrian Associated Charities, has created and continues to provide a campus which provides compassion, action and deed into life altering experiences. The research & application chemoprevention has significantly improved cancer survival rates in many childhood cancers. For example, in 1962, Acute Lymphoblastic Leukemia had only a 4% chance of survival. Today, nearly 85% of children can survive thanks to their collaborative efforts. The hospital has a mere 130 beds, but many hundreds of patients are seen on a daily basis as out-patients, in clinics, being housed in transitional housing, on the same campus, or in nearby hotels. No one who qualifies under their treatment protocols for study is refused due to financial constraints. Unfortunately, they cannot treat every condition, and currently, they have no protocol that involves NBCCS. Kristi hopes to improve those standings, and with the help of others create a window of hope for OKC and medulloblastoma.

If you or anyone in your biological family has been diagnosed with retinoblastoma or medulloblastoma, please let Sheila know, in order to assimilate information which may be helpful to draw a profile for future study opportunities.

For more information about St. Jude, visit www.stjude.org and click on any of the sub site information, including a warm, well organized "Patients & Parents" box.

Executive Director, Kristi Schmitt Burr, Jennifer Hendrick, and Trustee, Hans Muller

BCCNS Kids Attend Camp Wonder By Sandy Kleffman

Abridged copy originally published in the Contra Costa Times Sunday, June 26, 2005 on the front page and full pages 10 and 11

LIVERMORE - Natasha Starkey and Lizie Fernandez, best buddies at camp, prepare to launch into a song they composed.

"One, two, three, let's hit it," they chant, breaking into "Olivia, the Black-Nosed Bunny."

It's a scene that could be repeated at camps throughout the United States: two girls, 9 and 10, sharing the joyous creation of a close friendship. Except that behind a curtain next to the girls, a young boy with a serious skin disease screams in agony as adults change his bandages.

Natasha and Lizie undergo their own dressing changes while they sing. With sores and blisters covering much of their bodies, they have become pros at the painful procedure, accepting it with grace and good cheer.

Such are the incongruities of Camp Wonder, the only camp in the western United States for children with chronic and often disfiguring skin diseases.

Seventy-four boys and girls gathered at the Livermore camp last week. Away from the stares of strangers, they swam, rode horses, climbed a rock wall, slept in bunk beds and devised crazy skits. As much as possible, for five days, they left their diseases behind.

"The main thing I wanted to do is give the kids a sense of self-respect and let them know there are people who will accept them," said camp founder Francesca Tenconi. "Many of these kids are very ill, and there's always a question about who will come back next year."

Tenconi, a 21-year-old Walnut Creek resident, can empathize with the campers. A decade ago, she became one of the youngest people in the United States diagnosed with pemphigus foliaceus, a rare autoimmune disease that blistered her body, causing her skin to peel like tissue paper.

She shows few signs of the disease today, after discovering the best medications to use. But Tenconi has continued her dedication to the camp she founded after her 16th birthday.

Now in its fifth year, Camp Wonder is one of several weeklong events for children with a variety of life-threatening illnesses and disabilities held each summer at Camp Arroyo in Livermore.

Tucked in the tree-studded foothills south of Wente Vineyards, the camp is supported by the Taylor Family Foundation.

Eleven-year-old Alex Coil spent a sunny afternoon last week in the pool, sporting swimming trunks over his bandages.

"This is my favorite place in the world here at camp," the freckled boy said with a smile.

The Grass Valley resident arrived at the camp with his 10-year-old sister, Brandi. The siblings have a genetic condition known as epidermolysis bullosa, or EB. Lizie and Natasha also have the disease.

Structural weaknesses in the children's skin cause deep sores and scarring. The skin is so fragile that slight friction will make it blister or slough off.

The scarring is often so severe that fingers fuse to the palm, permanently shaping the hand into a fist. The webbing can also affect the feet, causing toes to curl into the skin.

Swimming is therapeutic. The chlorine keeps the sores clean and the soaking makes it easier to pull bandages off for a dressing change.

Yet, many EB patients find it difficult to use public pools at home. Some have been grilled about their condition or asked to leave by people worried that the disease is contagious. It is not.

There are no such concerns at Camp Wonder, where everyone is accepted and welcomed.

"I'm heavier than anything," Alex says as he steps out of the pool, his sopping bandages and a life vest weighing him down. He begins a slow, halting shuffle to his wheelchair, displaying his wry humor. "I'm a penguin," he says of his stiff movements. "Where's my limo?"

The camp has a "Club Med" where the children go for bandaging. Most EB patients have their dressings changed every other day, a two- to three-hour task. The host of medical professionals who volunteer at the camp make Club Med their headquarters.

This year, the medical staff included 10 doctors from UCLA, in addition to doctors rotated in from UC San Francisco, Stanford and elsewhere. Six full-time nurses, additional part-time nurses and numerous medical students rounded out the staff.

Older children with skin diseases frequently return to the camp to serve as counselors and role models. Beyond the feel-good experience, the camp provides a learning opportunity for the medical staff.

The campers have a variety of diseases, some common and some very rare, including psoriasis, eczema, ichthyosis, vitiligo, nevoid basal cell carcinoma syndrome and pemphigus.

Kayla Pelman, 13, of New Orleans, top left, and Jacey Childs, 13, of La Grande, Ore., enjoy themselves in the pool at Camp Wonder on Tuesday. Kayla lives with **basal cell carcinoma nevus syndrome**, which causes the development of cancerous cysts and lesions, and Jacey has ichthyosis, which causes an accumulation of dead skin cells.

"You don't see the whole picture of what skin disease is like when you just see kids in your office," said Stanford dermatologist Dr. Anna Bruckner. She treats Alex, Brandi and their older brother, Corey, who also has EB.

"It's wonderful to be able to help out in some way and see another side of their life."

Doctors rarely get to view the scope of an EB patient's sores because it takes too long to remove and reapply bandages during a typical visit.

"These doctors don't get to see how

Camp Wonder continued

these moms and parents are wrapping these kids," said Lauren Clark, a home health nurse for the Coil children. "Everybody does it a little bit different."

Bruckner took advantage of her time at the camp to help with Alex's dressing change. He first soaked in a tub while enjoying a vanilla milkshake and a movie.

"It was just nice to be able to spend some time with Alex," she said. "He's really good at air hockey. It's fun to see the kids being kids."

The volunteers try to minimize the focus on disease and make Camp Wonder about singing, dancing, arts and crafts and just having fun.

The camp has one paid staff member: director Barry Vigon, a big man with a booming voice who has worked as a comedy writer for such shows as "The Facts of Life," "Roseanne" and "Who's the Boss."

"I bring my comedy to camp," he said. "I get silly with them, and they love it. They give me so much more than I give them. They are so appreciative.

"For many of these kids who may not live long or have been suffering, this becomes the highlight of their year. Something happens as soon as they step on the property -- the bonding, the smiles, the experience of independence."

The camp turned away 17 children this year after reaching capacity. Tenconi admits those with the severest conditions first, the ones she figures may not have many summers left.

"Honestly, most camps just would not accept them because of their medical regimens," she said.

For some children with rare conditions, the camp provides the first time they meet others who have their disease.

"Some kids don't get to socialize like normal children do," said Pat McClelland, a UCSF nurse who has volunteered at Camp Wonder from the beginning. "They don't have many friends except their families."

Some have such visible signs of their maladies that they frequently draw stares in public. One girl told Vigon she cannot go through a day without getting teased or made to feel uncomfortable.

"When she comes to this camp, she can let her defenses down," he said. "Here they are in a completely relaxed environment. They share their stories and support each other."

During the day, the camp talk centers on typical kid stuff -- music, movies, the activities at hand.

But at night, when tucked safely in their beds, the kids often share information about medications and how they cope with their diseases.

Tenconi calls skin disease an "orphan field." Most of the conditions are so rare that pharmaceutical companies refrain from funding research on treatments, figuring they can make more money elsewhere.

Tenconi spends much of the year raising money to support the camp. She formed the Children's Skin Disease Foundation, a nonprofit organization to fund Camp Wonder and other programs.

The camp is free for the children.

"A lot of these families are burdened with huge medical expenses," she said. "I just did not want finances to be a factor in choosing who comes."

Few children seemed to form a closer bond last week than Lizie and Natasha, who first met at an EB conference several years ago. Lizie lives in Texas and Natasha in Ohio, so they rarely see each other.

At Camp Wonder, they chased each other in their motorized wheelchairs, giggling like any children playing tag.

They formed a band with Brandi and were eager to perform. Stepping out of their wheelchairs, holding a fake microphone and plastic guitar, they sang to recorded music, stepping in synch with each other. Natasha kneeled forward in a sizzling guitar solo.

When it came time to have their dressings changed, the two girls asked to be side-by-side to keep each other company. They sang songs and shared stories., "She accepts herself. She gets past the staring; she gets past the questions and just moves on from there. She gets a whole lot out of life. She enjoys things and appreciates things, more so, probably, than you and me.

"I hope she never looks in the mirror and says anything other than 'I like what I see.'"

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Noah Haugh (pictured below), says "Camp Wonder was fun. The coolest things were the counselors, rock climbing, singing and all my new friends. I got 2 awards for Best Dresser and Most friendly."

Adam Haugh *(pictured above) recalls, "At Camp Wonder, there were a lot of kids. They got lots of care. There were two rattlesnakes in the girl's bathroom. We had a roman race with all the kids, a zipline, free soda drinks and a dance. Some kids got sick and others had lots of girlfriends. We went swimming and made commercials, I danced for mine and received an award for Commercial Dancing Supreme. I am really excited about going next year."*

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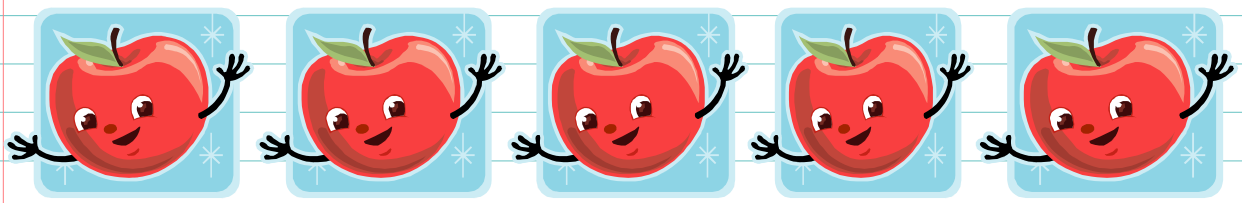

Upcoming Events:

September 21-24 Boston
American Association of Oral and Maxillofacial Surgeons Conference

October 8-11 Washington DC
American Academy of Pediatrics

October 22-25 Salt Lake City
International Society of Nurses in Genetics

January 23-27 Kauai
International Symposium in Oral and Maxillofacial Surgery

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