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Fall 2008 Ctĭ

Connecting pediatric oncology patients throughout the nation.

Hi, my name is Faith...

And I will turn 10 in November. When I was 3-1/2 I was diagnosed with leukemia. I spent 2-1/2 years going through a variety of chemotherapy and I didn't have any hair during that whole time.

I am lucky I had my cancer at a young age, as I do not remember a lot of what I went through. I do remember having a bad infection in my back from one of the bone

marrow biopsies and it was very painful; I was in the hospital a long time.

I also remember having the chicken pox while I was on chemo because I had to spend 10 days in isolation at the hospital and I got out the day before my 5th birthday. I also remember the chicken pox because the day after my

birthday, my dad got really sick - he got my chicken pox!

I am now 4 years cancer-free and I can't wait until my fifth year comes in 2009 because then I will be cured of leukemia and get to go on a trip to Disney World with my mom and dad and one of my friends. I am in fifth grade this year and my favorite activity is riding horses.

66 Yesterday's the past, tomorrow's the future, but today is a gift. That's why it's called the present. **??** Bill Keane

I have been riding every week for over two years. I can't do a lot of running because I have problems with the bones in my feet, and I can't swim much because I get bad ear infections, but maybe these things will get better as I get older.

Right now I am participating in the 2008 Cops for Cancer Tour de Valley. This is my fifth year with the

Faith models her Cancer Fears Me hat during her Cops for Cancer fundraising team and together we raise awareness of pediatric cancer and fundraise for research and Camp Goodtimes, which by the way is my favorite place.

This year I was able to raise over \$1,000 towards Cops for Cancer and next year I hope to raise over \$1,200 My mom and dad tell me a lot of kids and adults look up to

me because of all I have been through and that they learn to be strong like me. I just enjoy being a kid and helping out everyone I can no matter what type of help they need.

Faith was treated at BC Children's Hospital in Vancouver BC Canada.



66 When you come to the end of your rope, tie a knot and hang on. **99** Frankin D. Roosevelt



published quarterly by



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My daughter, Elisa, was diagnosed with Ewing's Sarcoma around her 8th birthday while in second grade. It started with mild leg pain. We thought she was experiencing growth spurts, but her leg started bothering her a lot more. She complained of the pain, then the leg started to swell. We decided to get her to a doctor for x-rays to find out the problem. The doctor suggested an MRI, but the problem was trying to come up with money for it.

We live in a community where people do not make much money. We figured we would have to make payments for the scan. The hospital was willing to work with us.



When it was time to go over the results, the doctor said the scan showed a mass. He referred us to a surgeon in Phoenix, Arizona. By this time, Elisa was having more problems with her leg – she was not able to use it at all. At the same time we were planning for a new baby; I had about seven weeks left of my pregnancy. We tried to keep things as normal as possible. My coworkers planned a baby shower. Elisa was looking forward to this very much, and also to see her cousin from Las Vegas. She was in so much pain but she put up a good front.

We went to the Mayo Clinic in Scottsdale, Arizona. A doctor there was going to work us in between surgeries. When he was able to meet with us, Elisa was in so much pain she could barely move her leg at all. He decided to do a needle-guided biopsy to determine what the mass was. We spent eight hours at the clinic; on the way back across town, we received a call from the Children's Hospital for an appointment scheduled for the next day. I called my friend and nurse for the doctor who referred us and told her the name. She had an idea that the prognosis was not good.

The next day we met with an oncologist and social worker from Phoenix Children's Hospital. The doctor told us Elisa was diagnosed with Ewing's Sarcoma. We were very upset. You never think this will happen to your kid. As we were talking to the doctor, Elisa heard us and realized she was sick. The doctor said it is a rare cancer for girls, more common in boys.

Tests were ordered. We notified our families who couldn't believe this was happening to a very active girl.

Elisa was scheduled to get her port-o-catheter done the next day and start treatment. She was very brave; she asked if it was cancer. She was familiar with it because her great- grandmother and aunt were cancer survivors.

The worst part was when they started the chemo; it made her sick. She is one of those girls who does not like to get sick in front of others. She had plenty of family support from visitors in the hospital. By the end of the visit, she was able to move her right leg some. The doctor was surprised; he said Elisa was about 15 days from losing her leg. I would say the first month was the toughest time for all of us. Elisa hated having to take medicine and shots. I was a pro at giving those since I had to do it twice a day for me.

Luckily, we had the support of family and friends to help with this process. Parts of John's family and mine would go with him to take Elisa back to Phoenix for treatments. I was not allowed to travel anymore because I was towards the end of my pregnancy. We live three hours away from her doctor and treatment center.

Elisa went through three more chemo treatments before I had her little sister. I almost gave birth when they were out of town but my doctor stopped the contractions. We were able to wait one more week.

It started out as a normal day but I knew something wasn't right with my body. My doctor checked and decided it was time. The best thing was I worked for the doctor who would deliver our baby. She sent me to the hospital to get monitored and prepared for a C-section.

www.coolkidscampaign.org

The Cool Kids Campaign is a 501(c)3 non-profit

devoted to improving the quality of life for

pediatric oncology patients and their families.



Elisa was in school. Her aunt said she would pick her up and take her home. I had Aitya Beth Toy around 6 p.m., weighing 5 lbs., 15 ozs. and 19 inches long. After the delivery, Elisa was allowed to see her sister. The hospital and doctor made an exception for her to be in the OB unit. I think this was probably the happiest moment for her; she was so proud to have a little sister. Elisa's oncology doctor called to wish us congratulations.

Then it was back to the reality of the treatments. I stayed home by myself with my sister's help for a few days. Elisa had a few more sessions before I was able to go with her. We were still getting a lot of support from family and friends.

My co-workers organized a fundraiser at a local park. One of Elisa's teachers held a coin drive.

I was then able to go to Phoenix with Elisa, for one of her five-day treatments. The doctor decided to try an outpatient procedure this time. Elisa did great the first four days, but on the fifth day, she had a seizure during lunch. I was very scared. I called the clinic who suggested I take her to the ER. The seizure was a side effect of one of the chemo drugs. Elisa had no idea of what happened at the restaurant; she couldn't remember.

Then a follow up x-ray was taken to determine the size of the tumor. From the chemo treatments, it looked like it had shrunk a lot. We were referred to the pediatric orthopedic surgeon who looked at the scans and wasn't sure if he was going to be able to save Elisa's leg; he warned us of the options.

We prepared Elisa for this, but the surgeon wanted further scans. He was hopeful about the upcoming surgery.

The day arrived; we hoped for the best. Family came to sit with us – a very long four hours. When the doctor came out, he said he was happy he was able to save her leg and put in an implant which was to grow with her as she grows. We were all so happy. Then Elisa had to start with physical therapy – not fun. The therapist came to the room to get her out of the bed and into a wheelchair. Elisa did not enjoy that since it was hard to move her leg, she was unable to bend it.

Then it was time to start the next session of chemo. She would have five weeks of radiation. The pathology report did not show the margin the doctor wanted. We spent more time in Phoenix. By this time, it was getting harder for John to take time from work. I had just returned to work after maternity leave, now I had to tell my boss I would have to go to Phoenix more often.

At one time we spent two weeks there; sometimes we'd go home on the weekends. There is no way we could have stayed if it wasn't for the Ronald McDonald House. Elisa was doing physical therapy at the clinic on another floor. We were so glad when the radiation stopped, then it was back to chemo every three weeks.

I was going to have to quit my job. John wasn't able to take her anymore. Basically, I spent the last three months of treatment with her in Phoenix. John went when it was only the 24-hour treatment since that was inpatient. The baby was not allowed in the hospital because of RSV restrictions. He came to Phoenix when she had her last round of chemo then when it was time to get the diagnosis that she was cancer free.

Elisa spent 10 months going back and forth to Phoenix for treatments.

Now we are glad to return to a normal life. Before, we could not plan anything. Elisa missed her aunt's graduation from college after developing an infection. We just went to Phoenix for a checkup and scan.

I am not allowed to work for Elisa to keep her insurance because of the pre-existing clause. She was diagnosed on a regular insurance plan but after I had the baby, I was made part-time and lost my insurance. We are only allowed to show so much income. We make too much for the state insurance.

I hope our story will help others to understand our experience.

By Todd Hartman (Dad)



hear one of our babies has leukemia hit our family hard. Finding out in September that our 2-year-old daughter has ALL (acute lymphoblastic leukemia) just a day before her 3rd birthday was not on our birthday gift list.

We should have seen the signs: loss of appetite, always sleeping, bruises that never faded, refusing to walk because her legs hurt, high fevers, and feeling sick to her stomach. We took her to the doctor, but he said she just had a virus, and that she's a growing child, she's going to have bruises. This went on for weeks. Becoming tired of all the excuses, we decided to take Karmen to Cincinnati Children's Hospital Medical Center.



With a concerned look they drew blood and took x-rays. After the results came back they wanted to admit her and do a bone marrow biopsy the next day. Ninety-eight percent of her blood had leukemia in it.

After she was there for a few days with a PIC line in, we tried to get a port placed. That did not go so well. Her blood pressure dropped and they thought that her lungs collapsed and stuck a needle in her side, but that was not it. We still do not know what happened. Was she so sick the antibiotics made it happen? Or was it a reaction to the medicine? That night it was hard to look at her with tubes in her nose, mouth, and side. She would wake up wanting to pull the tubes out because the medicine was not letting her sleep long. Because of that she was in ICU for two days.

While we were at the hospital she was able to get her medicine through her port. When we came home it was a different story. Trying to get her to take medicine was a battle. It was hard finding a way for a child to take nasty-tasting liquid because she is too small to take a pill. We were challenged with that for the next two years.

You never expect this could happen to your child, but if it does you ask "why?" Why did a sweet innocent child who has done nothing wrong develop a life-changing blood cancer? We were devastated. That was the day our whole life changed. That was the last day my wife Julie worked.



The first several months were very rocky. Adjusting to one income, we were living day to day, week to week. We were not able to afford things.However, we did have help, thanks to the hospital's caseworker. She put us in touch with several organizations which helped families dealing with cancer.

For Thanksgiving and Christmas 2007, the Kelly-Carol Foundation supplied our family with holiday dinners and gifts. They were not the only ones to help us in our time of need. My employer, Time Warner Cable, helped with food, money, and presents as well. Not only did they help us during Christmas, they have been very understanding about my daughter's condition and give me time off when I need it to take Karmen to the hospital.

With the help of our caseworker, Karmen was able to have a wish granted from Make-A-Wish. When we found out that Karmen was approved for a wish, we were so excited. We sat down and asked her her wish. She said, "I want to see Cinderella at Disney." With that said, we knew we were going to get a nice vacation away from everything.

We have tried to live as normal a life as possible, but it is hard. This year I was able to coach my son's baseball team again. Karmen started school this year. Slowly but surely we are trying to get back to normal life.

We know how it is to deal with a sick child. You just do it. Something in your body and mind clicks, and it feels like you have been doing it all along. We are so blessed that we live in today's world. If this would have been 10-15 years ago we would be looking over a grave of our daughter instead of at our daughter.

I can tell you one thing for sure – without the support of our family and friends we would not have been able to make it. Through this whole thing you have to remember that God has a plan for all of us and we may not like it or understand it, but God gives us special gifts. It is you who decides how to treasure them. Cherish each moment that comes. Otherwise, you will miss the special ones.



In May of 2006, 4-year-old Mark Isabelle had a doctor's appointment because he had a stomach virus that kept hanging on, and his coloring just didn't seem right. A full blood work-up was ordered, and the next morning Mark's parents, Wendy and Al, received a phone call telling them to immediately bring Mark to Fairfax Hospital. Later that day, they learned that little Mark had Leukemia – a parent's worst nightmare. The Isabelle family was already one that people admired and their home is a place where everyone –

children and adults alike - feel welcome.

Word quickly spread throughout the Springfield, VA, community that Mark was in the hospital, and the Isabelles' many friends, family members and neighbors rallied around them to offer prayers, friendship, hope, and support. This young, active, fun-loving family of five had just been turned upside-down, and no one could believe that this could be happening to them. Mark is the youngest of three children. His older sister, Megan, was 11 at the time of his diagnosis and his older brother, Chris, just 7. Megan and Chris were already making their mark in school by being involved in school activities and by being wonderful rolemodels among their classmates. Wendy and Al had always been active volunteers in their children's school and Wendy would often bring Mark along when helping out. As a result, Megan's and Chris' classmates all knew and loved Mark and his contagious smile and deep, irresistible dimples.

While Wendy and Al took turns staying with Mark in the hospital for the 10 days after his diagnosis, a giant-sized poster of Megan's softball team with get-well signatures from the girls appeared in Mark's room, along with stuffed animals, balloons, and cards from Megan's and Chris' classmates. Wendy was the coach of Chris' t-ball team at the time, and all of those teammates and families rallied around to lend their support as well. Megan and Chris were members of the neighborhood swim team, which quickly organized a biathalon fundraiser event along with a blood drive in honor of Mark. Fellow church members held Mark up in their prayers, and offered their friendship and assistance. The Isabelles had always given to their community and now those whose lives had been touched by their generosity were reaching out to help them.

All during that first summer, Mark continued to endure endless doctor's appointments and treatments; sometimes resulting in overnight stays in the hospital or day-long visits in the oncology clinic. Friends and neighbors coordinated meals and helped out where they could with Megan and Chris and their activities. Wendy and Al were determined to keep their family going as normally as possible and didn't seem to skip a beat when it came to making sure the needs of all three children were met. These two parents became more of a team than ever before - with Wendy's organization and "list-making" skills and Al's quiet strength – both of them keeping their faith first and their sense of humor in tact. They attended events and camps for kids with cancer and for siblings. They continued to invite friends over whenever Mark was feeling OK and his blood counts allowed it. They began a journey together as a family with their focus on supporting Mark and his fight against cancer, but at the same time completely dedicated to holding their family close and also supporting Megan and Chris. Mark couldn't ask for a more loving and proud older sister and brother. Their patience and tenderness with Mark is heartwarming and they are Mark's biggest fans of all.



Last summer, Al was transferred to the Richmond area, and the family had to face the stress of moving to a new city, along with the continued stress of their now year-long battle with Mark's Leukemia. Tearful goodbyes and promises to stay connected with their Springfield friends filled the summer of 2007, and soon Mechanicsville, VA, became the Isabelle's new home. After a year, they are now settled in, have made new friends and have been able to continue their friendships with those back in Springfield – many times meeting at Lake Anna at their beloved lake house (*"The House that Al Built"*).



Two years and a few months after being diagnosed, Mark continues to inspire and amaze us all with the many times he has fought off fevers, low blood counts and his famous mood swings. He accepts what he has to do - taking his "yucky' medicine, getting his port accessed and going through all of his treatments, but puts up quite a fight sometimes. Wendy and Al remember the advice of one of Mark's doctors who told them that they need to continue to discipline Mark just like they did before he had cancer. They have taken this advice to heart and with loving guidance Mark is a well-rounded, polite and kind-hearted little boy. He is "all boy," running, playing, riding his bike and keeping up with all of the other kids his age. Mark has an amazing smile, dancing eyes and an adorable language all his own, such as the way he says "bellwee" instead of "belly." He loves to sing and dance the latest dances. People just can't help but fall in love with this little guy and wonder at his bravery and wisdom at such at young age. When asked what he would do to fight cancer, he replied: "I will hit [it] and punch [it] and kick [it] and punch [it] in the back and the head."

Shortly after Mark's diagnosis, Wendy started a "Caringbridge" site for Mark, keeping his many

"fans" up-to-date on how he is doing and where he is in his treatment schedule. Almost every Tuesday, our emails contain a message telling us that Mark's Caringbridge site has been updated. On those days, many tears are shed (whether tears of joy or sadness) while looking at the latest pictures and reading Wendy's straight-from-theheart descriptions of Mark's doctor visits and the anxiety that goes with them. Wendy has said that making those journal entries is an outlet that helps keep everything in perspective. Intertwined in the entries are Bible verses, funny stories of Mark or other family members and friends, updates on Mark's continuing fight, and most of all her plea for all of us to "just keep praying." While Wendy is the author of the journal, Al is a constant source of support, many times behind the scenes, holding down the fort at home when Wendy and Mark make day-long or overnight trips to Fairfax, doing whatever he needs to do, juggling his work schedule to be by Wendy's side at every possible sporting event, school play or concert, and just being there for all to lean on.

Although this family has been given a huge burden to bear, they have taken this challenge head-on, doing what they need to do to help Mark fight to get well, keeping their priorities straight, and always taking the time to be there for each other and for Megan and Chris. Families dealing with a child with cancer have many struggles, and the Isabelles are no different. They may make it look easy, but the fears and questions are always there beneath the surface. Their faith in God and their devotion to family and love for each other all combine to give them the strength to provide a stable and safe home for Mark to get well. They continue to be a source of inspiration for us all.



Hi, my name is Tiffany...

and I have leukemia. I was first diagnosed November 2007 and I'm scheduled to be finished with treatment November 2009.

I truly thought I was going to die a few months after being treated for cancer, because after being put to sleep for a procedure, I saw a whole bunch of lights. I thought I was going to see "the white light" next, but luckily I didn't. It is very hard trying to win this battle with cancer. Through all of it I have experienced the loss of feeling in my feet, called neuropathy. I found out I may not get back the feeling in my feet until I stop taking one of the medications I must take.

I find peace by writing poetry. I have a true desire to publish my poems – I've written 416 – and I'm on my second book. I have a desire to share my style of writing and point of view with the public. Here are a few for you:

Peace

By Tiffany Brice

People need peace.



From the west side to the east.

Peace is a wonderful thing that everyone needs. Like a walk in the park with a beautiful breeze. Peace is like a nice breeze, but with a cherry on top, it's my kind of thing.

So make peace, and make it good, so people can dwell on it and say it is good.

Peace! Peace!

You see what it brings, so spread it around, and you'll see what I mean.

Sadness

By Tiffany Brice



Sadness is what I'm feeling. Lord! I need healing. I get yelled at and I want to shout. 100% of the time I don't know what it's about. I sit in my room and I cry myself to sleep. Lord! Sometimes I don't want to eat. They ask me what's wrong, but I cry some more. Why couldn't they see my sadness before?



We are **THANKFUL**for...

In preparation for the Thanksgiving season we wanted to highlight what some of our readers are thankful for...



We are thankful for family and friends. We are thankful for life and being able to live each day to the fullest. We are thankful for our doctors and nurses and all the staff at the hospital as they help keep Charlie in a good mood while going through chemo, radiation, and anything else we may have to go through at the time.

Charlie is thankful for his life. He even took a penny to a wishing well in my aunt's yard and said I wish I could grow up and be a big boy. He knows he has cancer *(neuroblastoma stage 4)* and he knows he is fighting against the odds.

Melissa Vandenburg

Mom to Charlie (4), Brendan (3) and Jade (2)



I am thankful to spend another day with my family. I am particularly grateful that I got to watch my daughter turn 13 in September, a major milestone for anyone, but in light of her rare genetic disorder, periods of kidney and heart failure, two kidney transplants (one seven years ago and one nine months ago) and battle with PTLD (lymphoma), this was an event to really, really celebrate! We are all grateful that at this moment there is no dialysis machine in our house anymore, no chemo to undergo, and no central or peripheral lines to maintain. We are grateful for our new home, the fact that medically things had quieted down enough for us to make a move, for Sierra's new school (and that she is finally back to school), for a new neighborhood playmate for Sawyer, and a return to a more "normal" life with much less time spent at doctor's offices, labs, and hospitals. We are also thankful for the 24 pills Sierra takes each day as they keep her healthy and her new kidney happy. We so appreciate the love and support from friends and family, and the kindness of acquaintances and strangers who have reached out and offered a hug or hand when we really needed it. We are grateful for all of it and that we keep getting the chance to spend one more day together.

Julie Ayers

Mom to Sierra (13) and Sawyer (9)





This Thanksgiving will be 17 months into our 5 year old daughter, Kayla's treatment for Acute Lymphoblastic Leukemia. She was diagnosed in June 2007. She has been in remission since the first month and has responded very well to her treatments. Our family is thankful for friends, family members, as well as strangers, who have helped us get through this ordeal. We could not have gotten through this without all of them. We have received support, calls, emails, meals, cards, gifts, care packages, etc. which has made it so much easier to get through the days. We are especially thankful to have our little girl still with us today.

Sincerely Thankful, **The Danzi Family**





We are thankful for God healing baby Samuel. We are very thankful to be a part of his life. We are also thankful for Dr. Shields at Will's Eye Institute in Philadelphia for saving Samuel's life, eyes, and sight. Also for Dr. Leahey at CHOPS and the wonderful nurses who administered chemotherapy during Samuel's illness. We thank you.

Most of all we are thankful to watch Samuel smile everyday. To see his happiness in his eyes makes us all the more thankful for having him here with us today alive, healthy, doing well, and in remission. Samuel is our miracle child who just celebrated his very first birthday and for this we are thankful.

Sabrina Snead

Mom to Samuel (13 months) and Dean





Thanks" giving \, n. 1. The act of rending thanks, or expressing gratitude for favors or mercies.

Thanksgiving means something different to everyone. To some it is the fourth Thursday in November, a day off of work, some college football, and good food. For most people, on Thanksgiving, they take a moment to reflect on the past year and the good things that have happened in their lives. This is the first in a series of articles we will publish addressing various aspects of wellness and practical steps you can take to enhance your family's health.

WELLNESS WORKS

by Kelli D. Anders, What's Your Why?, Ltd.

It's a rather nebulous phrase, and a popular term being tossed around as of late, but what exactly does "WELLNESS" mean?

WELLNESS DEFINED

Wellness is much more than simply the absence of sickness. Here are a couple of definitions:

- Wellness is an active process of becoming aware of and making choices toward a more successful existence. *(National Wellness Institute)*
- Wellness is a positive, day-to-day approach to a long, healthful, active life. (*"Wellness Letter;" UC Berkeley)*

It is optimal physical, mental and emotional wellbeing, a preventive way of living that emphasizes personal responsibility for making the life-style choices and self-care decisions that will improve the quality of your life.

In the past few decades, however, the dramatic rise in incidence of illness and disease has given some people a more cynical outlook on health and wellness.

"It's no longer a question of staying healthy. It's a question of finding a sickness you like.

—Jackie Mason (1934 -)

While this seems a rather silly exaggeration, the alarming trends we are experiencing in Asthma, Allergies, ADD/ADHD, Autism, Cancer, Headaches, Infertility, Fibromyalgia and other Auto-Immune Diseases, etc. have caused varied reactions – for some, mere pause or curiosity; but for many others, downright frustration, fear and justifiable concern.

KEY FACTORS & COMMON OBSTACLES

What are the key factors and common obstacles to achieving our desired level of Health and Wellness?

Environment: Increased exposure to harmful chemicals Nutrition: Nutrient deficiencies in our soil Weight Management: Changes in U.S. diet **Exercise:** Struggle for endurance and noticeable results

ENVIRONMENT, I.A.Q. (Indoor Air Quality)

Typically when we think of Wellness – or lack thereof – we primarily consider the last three factors (*nutrition*, *weight mgt. and exercise*, *and their cause-&-effect relationship to illness*, *obesity and disease*).

But there's another major player in this game, one that you may not have considered or put much weight into, but deserves your undivided attention. And that is your environment – in particular your home environment, the quality of the air that you breathe and the things that touch your skin every day of your life.

There is an overwhelming amount of research and data linking our health and the use of or exposure to chemicals in household cleaning and personal care products.

Some Facts to Consider

Dr. Joyce Woods, in her book <u>Create a Safe &</u> <u>Healthy Home</u> (©1996), supplies us with some statistics about our greatest exposure to chemicals being right in our own home:

- More than 72,000 synthetic chemicals have been produced since WWII.
- Less than 2% of synthetic chemicals in wide spread use have ever been tested for toxicity, birth defects or their mutagenic or carcinogenic effects.
- The average home today contains 62 toxic chemicals, more than a chemistry lab at the turn of the century.

The EPA reports that toxic chemicals in our home are 3 times more likely to cause cancer than airborne pollutants.

Asthma, for example, has increased 75% since 1980 and accounts for approximately 10 million physician office visits, 400,000 hospitalizations and 1 million emergency room visits every year.¹

Allergies are the 6th leading cause of chronic disease in the U.S., costing \$18 billion annually.²

EXPOSURE

So how do we come into contact with these chemicals? There are 3 primary ways...

Ingestion

- We swallow small amounts of chemicals when we gargle, or eat foods from dishes cleaned with chemicals that still contain a thin residue.
- Ingestion also brings to mind the image of a young child opening the cabinet under the sink and drinking something deadly.
- Of the 5-10 million accidental poisonings reported to the US Poison Control Centers each year, nearly 1.5 million of them are accidental ingestions; the majority of the victims are under the age of 12 and have swallowed a cleaning or personal care product.
- After all, they can't read warning labels and to them, ammonia looks like apple juice and a mothball looks like a piece of candy.
- In fact, more children under the age of 4 die of accidental poisonings in the home than are accidentally killed with guns at home. ["Accident Facts" National Safety Council, 1993]

Inhalation

- We breathe chemical vapors from the "offgassing" of household products in the air.
- Houses today are being built more 'energy efficient' to keep in the heat and AC, but according to the EPA, most homes have airborne concentrations of hazardous and toxic chemicals that are 2 5 times higher indoors than outdoors, so clearly, the fumes from these products are staying trapped inside as well.
- It may surprise you to learn that poisoning by inhalation is more common, and can be much more harmful, than ingestion. When something harmful is swallowed, the stomach actually begins breaking down and neutralizing the poison before it is absorbed into the bloodstream. However, when you inhale toxic fumes, the poisons go directly into the bloodstream and quickly travel to organs like the brain, heart, liver and kidneys.

Did You Know...

Warning labels refer only to toxic hazards from ingestion of a chemical (10%)?

90% of health problems caused by chemicals are by the inhalation of vapors and absorption of chemical particles?

Dermal Absorption

- Finally, you need to realize the potential threat absorption poses.
- One square centimeter of your skin, an area less than the size of a dime, contains 3 million cells, four yards of nerves, one yard of blood vessels, and 100 sweat glands [Poisoning our Children, Nancy Sokol Green].
- So any chemical that touches the skin can be absorbed and spread throughout the body.
- This is why nicotine, heart medicines, birth control and other prescriptions are now being administered through transdermal patches.

Important Tip:

NEVER mix two cleaners of different kinds together, especially if one contains ammonia and the other contains chlorine.

Example: We spray our showers and baths with a cleaner containing chlorine and let that sit while we spray our medicine cabinet with glass cleaner containing ammonia. This can produce a gas called chloramine, and breathing fits fumes could be fatal.

Children are Uniquely Vulnerable

Until a child is approximately 13 months of age, they have virtually no ability to fight the biological and neurological effects of toxic chemicals.³

Pound for pound of body weight, children drink more water, eat more food, and breathe more air than do adults. The air intake of a resting infant is twice that of an adult per pound of body weight.

These patterns of increased consumption reflect the rapid metabolism and growth of children. Combine this with their characteristic hand-tomouth behavior and their likelihood of playing close to the ground, and the implication for environmental health is that children will have substantially heavier exposures pound for pound than adults to any toxins that are present in water, food, or air.

Children's Developmental Processes are Easily Disrupted

Many organ systems in young children - the nervous system, the reproductive organs, and the immune system - undergo very rapid growth and development in the first months and years of life.

The nervous system is not well able to repair any structural damage that is caused by environmental

toxins. Thus, if cells in the developing brain are destroyed by chemicals such as lead, mercury, or solvents, or if vital connections between nerve cells fail to form, there is high risk that the resulting neurobehavioral dysfunction will be permanent and irreversible. The consequences can be loss of intelligence and alteration of normal behavior.

We all just assume... "They wouldn't sell it if it wasn't safe...would they?"

LABELING LAWS

- There are 4.5 million chemicals known

 approximately 80,000 in commercial distribution. It takes a team of scientists, 300 mice, 2-3 years, and approximately \$300,000 to determine whether one suspect chemical causes cancer.⁴
- Chemicals that can cause death, cancer, birth defects, respiratory illness and central nervous system (CNS) disorders (like Alzheimer's disease, Multiple Sclerosis, Parkinson's disease, Epilepsy and Schizophrenia) appear in most of the cleaning and personal care products in your home.⁵
- The US Federal Code of Regulations exempts manufacturers from full labeling of products if used for personal, family or household care.⁶
- A product that kills 50% of lab animals through ingestion or inhalation can still receive the federal regulatory designation "non-toxic."⁷

FIRST STEPS

What steps can we take to reverse these disturbing statistics? With the current trend in "going green" it is easier than ever to find or make safer alternatives to the caustic cleaning chemicals in commercial distribution. Even the major consumer goods manufacturers are responding to the demand for healthier cleaners with new ecofriendly brands.

Elimination⁸ & Transition

 Gather up the unacceptable cleaning agents in your home and garage. While you're at it, include cans of old pesticides and paints, too. For many products, I don't recommend "using it up" before disposal because of increasing evidence that many commercial products carry health risks. You may even have a product that, without being aware, has long since been taken off the market for safety reasons.

- Contact your county health department or recycling center to find out when and where you can safely store or dispose of hazardous waste. Do not pour these materials down the drain or throw it in your regular trash.
- 3. If you spill anything, try to absorb it with unperfumed, pure clay kitty litter, or a disposable diaper, as these two items don't react with chemicals. Keep children and pets away from the area and try to ensure as much ventilation as possible.
- 4. For the health of your body, your family and the environment, commit to using noncaustic cleaners. With a little homework, or guidance from the internet or someone like me who specializes in this area, you will discover that these products are easily accessible and don't have to cost you more than their toxic counterparts!



Personally, the facts and statistics I discovered in researching the safety (or lack thereof) of the ingredients in every-day personal and cleaning care products, as well as some foods, created much inner turmoil, frustration and downright anger. Rather than stand by feeling helpless and continuing to watch people innocently suffer because they honestly don't know any better, I decided to channel those feelings into action. What's Your Why?, Ltd. raises awareness and enhances people's quality of life through education about these matters, as well as providing safer alternatives. I have teamed up with Cool Kids to offer information and resources for non-caustic cleaning, personal care and over-the-counter pharmacy products to the families connected to this awesome organization. For more information, please contact me at 410.592.5763 or whatsyourwhy@iglide.net.

¹ "Trends in Asthma Morbidity & Mortality" American Lung Association Epidemiology & Statistics Unit, March 2003

²National Institute of Allergy & Infectious Diseases, January 2002

³ <u>Raising Children Toxic Free</u> © 1995 Needleman, M.D. and Landrigan, M.D.

⁴ "Our Stolen Future" NY Times Book Review, as cited in Toxic Time Bombs © 1997, Dr. John Buckler, World Solutions, Ltd.

⁵ Is Your Home a Healthy Home? © 2002, John K. Beaulieu

⁶ USA FCR: Sec.1910.1200C, Title 29, Sec.1500.82 2Q1A

⁷ <u>Is This Your Child's World?</u> © 1996 Doris Rapp, MD Bantam Books

⁸ Clean & Green ©1994, Annie Berthold-Bond



Kelli Anders, President & Owner of What's Your Why?, Ltd., launched her health and wellness training and consulting business after losing her brother, Casey, to Non-Hodgkin's lymphoma in 2001. Her passion is educating families about how to shop for safer, healthier alternatives for prevention and remission of various health concerns. Kelli is also a certified Living Foods Chef & Educator, and believes that food choices play an enormous role in health, vitality and longevity.



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Quick

IND BEND Why are some letters above the line and some letters below? Over & Under AEFHIKLMNTVWXYZ BCDGJOPQRSU Find the Words that Fit Some Thanksgiving Facts...

- The Turkey Trot, a ballroom dance in the 1900s, was named for the short, jerky steps of the turkey. It became popular mainly because it was denounced by the Vatican as "suggestive."
- Turkeys are known to spend the night in trees! (Maybe to escape the Thanksgiving table?)
- Turkeys can drown if they look up when it's raining!
- The average age of the Mayflower passenger was 32. The oldest Mayflower passenger was 64.
- There was no milk, cheese, bread, butter or pumpkin pie at the original Thanksgiving Day feast.
- Fresh cranberries are ideal for cranberry sauce. Cranberries of the highest quality will always bounce! (If you try this at home, please wash the cranberries before eating.)
- President Abraham Lincoln established the original date for our National Thanksgiving Day celebration in 1863.
- President Thomas Jefferson scoffed at the idea of establishing a national "Thanksgiving Day."
- Congress did not declare Thanksgiving a national holiday until 1941.
- The average person consumes 4,500 calories on Thanksgiving Day. (Now that's a lot of turkey!)
- Fossil evidence shows that turkeys roamed the America's 10 million years ago.

Directions: Find the words that fit.

Example: 16 = O in a P ... You need to figure out what the "O" and "P" stand for. Answer: 16 Ounces in a Pound

26 = L of the A

- 1) 7 = D of the W 2)
- 31 = F at B R 3)
- 101 = D 4)
- 52 = C in a D 5)
- 7 = W of the W 6)
- 88 = P K 7)
- 13 = S on the A F 8)
- 365 = D in a Y 9)
- 18 = H on a G C10)
- 90 = D in a R A 11)
- 200 = D for P G in M 12)
- 50 = S in the U 13)
- 3 = B M (S H T R)14)
- 4 = Q in a G 15)
- 24 = H in a D 16)
- 4 = W on a C 17)
- 1 = H on a U18)
- 60 = S in a M 19)
- 9 = P on a B B T20)
- 40 = D and N of the G F 21)
- 28 = D in F 22)
- 64 = S on a C B 23)
- 28 = D in F ----- Days in February 22)
- 64 = S on a C B ----- Squares on a Checker Board 23)

Number Fun! This is so cool!

- 1) Pick a number between 1 and 10 (including 1 or 10).
- 2) Multiply your number by 9.
- 3) Add the digits of that number together. (If you got 52, add the 5 and 2 to get 7.)
- 4) Subtract 5 from that number.
- 5) Find the letter in the alphabet that corresponds to the number created in step four.
 - ex: 1=A, 2=B, 3=C,...
- 6) Pick a country in Europe that starts with the letter you found in step five.
- 7) Pick an animal that starts with the last letter of your country.
- 8) Pick a color that starts with the last letter of your animal.
- 9) Let me guess what you got!! Turn to page 12 to see our guess...

(continued from page 6)

For our family, there are thoughts of thanksgivings and blessings throughout the year. We have learned to try to look at the bright side of every situation, no matter how grim it may appear. This was not an easy lesson, but it has been one that has helped us through many rough times. When MacKenzie had her first brain surgery to remove an egg-sized malignant tumor, we were devastated. She went into the operating room a highly coordinated gymnast. She came out unable to communicate or move on her own. We sat at her bedside and mourned the loss of 'our MacKenzie' and feared what her future would be.

One day while we were sitting in the PICU, when blessings seemed impossible to see, Dr. Ben Carson came to us. He asked us to look around at the other patients, and told us to be thankful for how MacKenzie was doing. She wasn't where we wanted her to be, but she was alive and had a much better chance then most of the other children in the PICU. That is the day I started looking at Thanksgivings instead of desolation.

For over 150 weeks, MacKenzie has had to face many obstacles.

• She has been diagnosed with brain cancer twice -

letters on the bottom all have rounded edges.

nswer to Over & Under

The letters on top of the line all have pointed edges, the

we are thankful we caught it relatively early and we live close to world renowned doctors.

- She has had two major brain surgeries and several other minor surgeries we are thankful for steady hands and brilliant surgeons.
- She has had to re-learn how to speak, feed herself and walk - we are thankful for educated and dedicated therapists.
- She has not been able to consistently attend more than a few hours of school at a time since the middle of third grade - we are thankful for a helpful school district and a loving tutor.
- She has not been able to experience the normal life of a "Tween" we are thankful for cancer support organizations and friends of all ages.

The list goes on, but for every obstacle, there is a thanksgiving that fits.

When Kenzie's cancer came back and we were told how devastating the diagnosis of the relapse was, we had a hard time looking at thanksgivings. I put my head down on my mother's lap and I sobbed my heart out, but then I had to stand up, wipe away the tears, and take care of MacKenzie and the rest of my family. When we were allowed to see Kenzie in the PICU, the first thing she asked was if the cancer was

```
back. Yes. "Do I have to have more radiation?" No.
"Okay." The thanksgiving? My little girl, at 10 years
old, had the strength to fight brain cancer... again.
```

Between Thanksgiving and Christmas this year, Kenzie will have her next MRI. Each time she was diagnosed, it was in this timeframe. To celebrate Thanksgiving we will go back to Myrtle Beach as a family, just like we did in 2005 and 2007. Each time she has been diagnosed, we had just been to Myrtle Beach for a family vacation. We are thankful that we can enjoy another week of vacation together as a complete family.

One day someone stopped me in the store and asked me why I was always happy. "How can you be laughing? Kenzie's cancer is back..." How could I not be laughing? Kenzie's cancer was back. Statistically she should die from it, but did I want her time to be spent around sadness or a joyful life? The thanksgiving? Someone, 150 weeks ago, told me to look around and be thankful. Enjoy what we have been given, every little bit of it. We are blessed. We are thankful.

Sue Stuck

Mom to Katie, Lauren, MacKenzie and Nikki



More Thanksgiving Facts...

- Americans feast on 535 million pounds of turkey on Thanksgiving.
- According the U.S. Department of Agriculture, more than 45 million turkeys are cooked and eaten in the United States at Thanksgiving. That number represents one sixth of all the turkeys sold in the U.S. each year!
- Benjamin Franklin wanted the turkey to be our national bird.
- Domesticated turkeys cannot fly, however wild turkeys can fly up to 55 miles per hour over short distances.
- Only male *(tom)* turkeys gobble. Females make a clicking noise. The famous gobble is actually a seasonal mating call.
- Contrary to popular belief, the Pilgrims did not have big buckles on their clothing, shoes, or hats.

23) 64 = 5 on a C B ------ Squares on a Checker Board 22) 28 = D in F ----- Days in February D = D and N of the G F ----- Days and Nights of the Great Flood P = P on a B B T ----- Players on a BaseBall TeamotuniM & ni sbnoos2 ----- M & ni 2 = 03 (91 nooinU a no noH ----- U a no H = f (8fThe second seco 16) 24 = H in a D ----- Hours in a Day nollab a ni strau Ω ----- ∂ a ni $\Omega = 4$ (∂ f 14) 3 = B M (S H T R) - ----- Blind Mice (See How They Run)noinU sht ni setstS ------ U sht ni S = 0 (E f 12) 200 = D for P G in M ------ Dollars for Passing Go in Monopoly əlpnA trigifi s ni zəərbəD ----- A A s ni D = 00 (11 10) 18 = H on a G C ------ Holes in a Gold Course 9) 365 = D in a Y ------ Days in a Year 7) 88 = P K ------ Piano Keys blow of the World ∇ = V of the World ∇ = ∇ (6) 5) 52 = C in a D ----- Cards in a Deck snoitsmlsd ----- D = 101 (4) 3) 31 = F at B R ------ Flavors at Baskin Robbins 2) 7 = D of the W ------ Days of the Week to the Alphabet $\Delta = L$ of the Alphabet $\Delta = -L$ of the Alphabet Hnswers to Words that Hit

How does this work?! In the first step, you picked a number between 1 and 10... If you picked 1, you got 9. If you picked 2, you got 18. If you picked 3, you got 27. If you picked 4, you got 36... Mo matter what number you started with, when you do step two (adding the digits of your number created in step one) you get 9! Then you get 9! One country in Europe that starts with D! (If you didn't get one country in Europe that starts with D! (If you didn't get fair saying, "Dutchland!") Most people think of a kangaroo, fair saying, "Dutchland!") Most people think of a kangaroo, fair saying, "Dutchland!") Most people think of a kangaroo, fair saying fine dign work on your geography! And no Denmark, you need to work on your geography! And no Denmark, you need to work on your geography! And no fair saying, "Dutchland!") Most people think of a kangaroo, fair saying fine dign fine dign fine dign fine didn't get fair saying fine dign fine dign fine dign fine didn't get

Did you say an Orange Kangaroo in Denmark?

ns we are to Number Fun



How your family and friends can help raise money for you!

Show off your strong, positive attitude towards cancer!

Welcome to **Cancer Fears Me** – a strong, positive mindset for those living with cancer, their support groups and caregivers.

We know fear is a dominant emotion when someone is given a diagnosis of cancer. Cancer Fears Me turns that fear around and puts you in control.

Cancer Fears Me was born after years of working with families living with cancer and recognizing how much fear this terrible disease causes. How these invading cells try to take over our bodies and our life.

Whether you are the patient, a caregiver or part of the patient's support group of family and friends, you can show who is in control – YOU!

We have developed a line of merchandise and apparel with the Cancer Fears Me logo to help fund our programs for the Cool Kids Campaign, including the Cool Kids Connection.



66 a strong, **positive** mindset for those **living** with cancer, their **Support** groups and caregivers **9**9

Cancer Fears Me and the Designated Patient Fundraising Program

Introducing, **Designated Patient Fundraising!** Through this program, your family, friends, school, anyone who supports your fight against cancer, can now sell the Cancer Fears Me gear and 25% of their sales will go directly back to you!

It's so easy. All you have to do is fill out a verification form that you are a current patient signed by an authorized personnel at your hospital. Then you will be registered with us and we will assign you a patient #. To get a verification form you can download one off our website or the Cancer Fears Me website or call us and we will send you one.

Then you or anyone you know can request the CFM catalog and order forms, hand them out to your supporters, have them place their orders with you as the designated patient, and we will send you a check for 25% of their sales.

Anyone can do this for you. And as many people as possible can do this for you. There is no limit on how much money will be sent to you and there are no restrictions on what you do with the money.

We know families living with cancer have many financial burdens. Cancer Fears Me is a way for you to directly raise money for yourself.

The remaining money is used to offset the costs of the items as well as helping the other families in need through the Cool Kids Campaign.

Anyone diagnosed with cancer is eligible, pediatric or adult oncology patients. And anyone can sell for you.

For more information or to get started with the Cancer Fears Me Designated Fundraising Program, contact Sharon Perfetti at 410.560.1770 or email at sharon@bfpf.org.

Check out our website www.cancerfearsme.org.



Cool Kids and Cool Caregivers

By Molly Lauryssens

Give me the beat boy to free my soul, I want to get lost in rock and roll and drift away. There's just something way too cool about 6-year old Mark Isabelle who sings his way straight into hearts with his very own rendition of "Drift Away." He loves singing and, man- can he belt out a tune! During his interview, Mark also sang the Richard Marx tune, "Right Here Waiting." His spunk is contagious and he really likes getting his groove on with music. How about you?

Claire Keller loves working with children in New Orleans. Even though her least favorite thing to do is "cleaning up the playroom" she enjoys doing lots of fun things with her patients. The Zoo and Bug Mobile visits the hospital monthly and Claire likes learning about all the different animals and bugs. She's even bold enough to touch them! Are you?

Check out their profiles to see if you share any other common interests with Mark Isabelle and Claire Keller.

Mark Isabelle

Leukemia

What is your name? Mark Isabelle Where do you live? Mechanicsville, Virginia What grade are you in? First How old are you? 6-years old When is your birthday? December 24 What is your favorite subject in school? Math



What is your favorite food? Waffles and Rice"Christmas" Treats (*Rice Krispies Treats*) *What is your favorite food for Thanksgiving Day?* All the food!

Do you have a BFF? Yes. What is his/her name? Sean



Who is your favorite celebrity (sport or entertainer)? Me and me, I am a football and baseball celebrity!
What types of things do you like to do for exercise?
I like to play soccer. I swim all my strokes-all of them, even the butterfly. I like baseball.
What qualities do you have that make you a Cool Kid?
Because I'm special, because I'm nice.
If you were the President of Whoville what would be your first act as the ruler? Don't have to go to the doctors. And no school.
Do you like dogs, cats, earthworms, birds? Dogs What is your favorite cereal? Cocoa Puffs
If you could be anything in the world, what would it be

when you grow up? A rock star because I like to sing.What is your favorite movie? Snowbunnies.Favorite television show? Avatar.

What is your favorite video game to play? Mariocart *What is your favorite sport?* Soccer

What kind of music do you listen to? Rock and roll Do you have any brothers or sisters, if so- what are their names and how old are they? Megan, 14, Chris, 10. What is your favorite fruit or vegetable? Apples and sweet potatoes.

If you were stranded on a deserted island, what three things would you like to have? Toys, guitar and a surf board.

What are you most grateful for? My blanket. I call it my "daddy's shirt." (His mom, Wendy explains –"He lost his blanket when he was young and somehow became attached to this old beat up shirt of his daddy's. Since his diagnosis with Leukemia, Mark's blanket has become one of his coping devices.) If you were one of the seven dwarfs, which one would you be? Happy. Why? Because I just love being happy. If you could meet and interview one famous person who would it be? Michael Phelps

What is the first question you'd ask? Great job with swimming! Where do you put all your gold medals and were you nervous?

Since Thanksgiving is coming up, do you have any special plans for the big day? I'm going to grow a sunflower.

What are you most thankful for? The songs.

Claire Keller

Tulane Hospital for Children, New Orleans, LA

Where do you live? I live in New Orleans, LA. *What is your title?* I am a Certified Child Life Specialist.

What do you do? I work with patients and their families to help them cope and understand everything about their illnesses. I teach kids about what it means to have cancer and what kinds of things will be happening to their bodies. I also spend lots of time doing fun things with kids while they are in the hospital. For example, the zoo and bug mobiles come every month to visit and we get to touch the animals and bugs and learn interesting things about them!

What is your favorite thing about your job? My favorite thing about my job is helping kids understand that the hospital isn't always a scary place. I also love the time I get to spend with the patients and learning about what kinds of things they like to do when they aren't inpatient.

Least favorite thing about your job? Helping to clean up the playroom!

What time does your normal day start? My normal day starts at 9.

What is your favorite sport to watch? I really like to watch college and professional football... Roll Tide! And Go Saints!

To play? I have no athletic bones in my body! I'm really only good at bowling on the Wii in the hospital playroom!

Do you have any children of your own? Nope! *What do you like to do for fun?* I love to go swimming at the pool or at the beach! And I love spending time with friends and watching good movies! *What is your favorite movie?* Ducktales: The Adventures of the Lost Lamp

What is your favorite book? I have two! Night Jasmine by Marylou Widmer and Beach Music by Pat Conroy

What was your favorite subject growing up? History Favorite cereal? Pops Favorite dessert? Soft serve vanilla yogurt with rainbow sprinkles Favorite kind of food? Olives Favorite board game? Cranium Favorite card game? Battle or old maid What is your favorite food during the Thanksgiving celebration? Mashed potatoes and gravy. Cats or dogs? Puppies Favorite celebrity? Bill Cosby Favorite season? Spring



If you could have dinner with one person, dead or alive,

who would it be and why? This is tough! I think I would say that I would like to have dinner with my Pops, who is my grandfather that died of brain cancer 4 years ago. The time he was diagnosed till the time he died was very short and I was away at college for most of it. I would love to have dinner with him now to be able to fill him in on my life and talk with him about all of our great memories together.

What is on your IPOD? If you don't have one, what CDs are in your car right now? I love Dave Matthews and Norah Jones

What are your Thanksgiving Day plans? For

Thanksgiving I will probably have dinner with my dad and little brother. Nothing fancy, but just family togetherness!

What are you most thankful for? I am most thankful for my family!

So **Cool Kids Connection** is setting out to get to know you. After all, you provide us with some of the most inspirational and motivational stories. Don't be shy, we want to hear from you! Contact Sharon at sharon@bfpf.org if you would like to be interviewed for Cool Kids and Cool Caregivers for the next edition! Or of course, just send us your own article, artwork, photo or poem!



Seek the wisdom of the ages, but look at the world through the eyes of a child.
Ron Wild



You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I have lived through this horror. I can take the next thing that comes along.' You must do the thing you think you cannot do. ?? Eleanor Roosevelt



