



Dani's
FOUNDATION

Annual Report
December 31, 2009

1600 Broadway, Suite 2400, Denver, CO 80202 303.601.1881 www.danisfoundation.org

Dani's FOUNDATION

Dani's Foundation was formed in memory of Dani Stell, an active, bright and social young woman who loved fashion, dancing, school and friends.

Dani's Foundation was established in 1999 with the goal of lending support and resources to Ewing's patients and family members, advocating for better treatment protocols for all cancer patients and working toward finding the cause and the cure for Ewing's Sarcoma and the other forms of pediatric sarcomas that are affecting and taking the lives of children and young adults.

Since its inception, Dani's Foundation has supported local and national programs, education and research that are aimed at eradicating Ewing's Sarcoma and other forms of pediatric sarcomas.

We need your help *NOW* to make a difference in the lives of those patients currently affected and those yet to come. By working together, we can make tomorrow a brighter day for our most precious natural resource: our children!

For more information on Dani's Foundation, visit our website at

www.danisfoundation.org

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THE SEASON OF GIVING STARTS NOW

I am very upset - Why? Because children are still dying from the type of cancer that took my daughter's life ten years ago. The outcomes for young people today, diagnosed with Ewing's Sarcoma and the other forms of pediatric sarcomas, are the same as they were 10 years ago. I believe strongly that there is much more that can be done and I know, in my heart, that we can have a tremendous impact in the coming year if we can all join together and make a commitment toward defeating these deadly childhood opponents!

As each of us prepare to embark on the *Season of Giving*, I am making an impassioned plea to you with the goal of garnering a year end tax-deductible gift to Dani's Foundation so that we may continue our effort in the Campaign to End Ewing's and the other forms of Pediatric Sarcoma. If every person who is reading this newsletter would make a \$25 donation to our Foundation by the end of the year, we could offer greater support to the Ewing's community. Might you consider forgoing the purchase of *just one* holiday gift this year and send that money that you would spend on that gift to Dani's Foundation? I am quite certain that your family member, friend or business associate will be deeply touched by this gesture, knowing that you are honoring them with this very important gift that will serve to help so many. One can only imagine what these holiday donations can mean to our Foundation and to those that we seek to serve.

- A donation of \$25 will help us in underwriting the continuation of our website www.danisfoundation.org. This is the most important resource that we can offer to the Ewing's and Pediatric Sarcoma community. Your gift will keep this website operational and help us in updating vital information and resources for patients, family members, caregivers and medical professionals.
- A donation of \$50 will assist us in underwriting the supplies necessary to launch our Pediatric Sarcoma Community Education Program in 2010. As you will see from the story on page 3, this program is needed to insure that Dani's Foundation takes the lead in educating the Colorado community on the symptoms of pediatric sarcoma with the goal of seeking earlier detection and ultimate survival.
- A donation of \$100 and above can help us to continue our efforts to fund cutting-edge research that is desperately needed by today's scientific investigators. In today's economic crisis, funding for research has been cut and the research for pediatric cancer will suffer the most with these cuts. Present financial cuts could result in putting 20 new pediatric cancer studies on hold. In addition, 400 children will not have the opportunity to participate in clinical trials next year. This is unacceptable. We cannot leave better treatment options further from reach. We need to act NOW and insure that research continues. Our children are counting on our support!

I established Dani's Foundation in memory of my daughter, Daniele Stell, who last her battle to Ewing's Sarcoma ten years ago. Many of you know the story of Dani and her valiant battle against this dreadful disease. It was awful for Dani and for those of us who loved and cared for her. Dani's story mimics so many other stories and that is why this Foundation is dedicated to each and every patient, family member, caregiver and medical professional who are waging the battle against Ewing's Sarcoma and those other pediatric sarcomas that are still affecting and taking the lives of children and young adults. The madness needs to stop and we need you help if we are to make a difference in the days ahead! Your support is the key to our ultimate success!

I realize that this has been a tough year for all of us in regard to the global financial crisis, but try to imagine what this year has been like for those patients and their families who have been diagnosed a major illness and for those scientific investigators who are seeking funding in order to continue their work in finding the causes and cures for major diseases. These are the individuals that need us now, more than ever before, and I am asking for your support if we are to continue our efforts to beat Ewing's and the other forms of pediatric sarcoma. Whatever you can do, we will gladly accept your support with the goal of expanding the scope and service that we seek to provide.

In advance, I thank you for your continued support of Dani's Foundation and honoring my passion to assist the Ewing's and pediatric sarcoma community. Your friendship and love has enabled Dani's Foundation to thrive and we will look forward to keeping you actively involved in our quest to End Pediatric Sarcoma.

My best wishes to you and yours for a wonderful holiday season and a New Year filled with health and happiness!

Michele Ashby, Founder & President

Dani's Story



*"Mom,
we're picked for a reason!"*

With that statement in
mind,
Dani's family and friends
gathered together
following her death
from Ewing's Sarcoma
and worked to establish
Dani's Foundation.

**Dani's
FOUNDATION**

1600 Broadway

Suite 2400

Denver, CO 80202

303/601-1881

www.danisfoundation.org

Dani's Foundation was formed in memory of Dani Stell, an active, bright and social young woman who loved fashion, dancing, school and friends. She aspired to become a fashion designer after graduating from college.

Dani was 18 years old when she found a lump on her side. After six months, she was diagnosed with Ewing's Sarcoma, a rare type of cancer that typically affects children and young adults.

By the time of Dani's diagnosis, the cancer had spread to her lungs. Although she showed no outward symptoms other than the lump on her side, Dani was in critical condition at the time of her diagnosis. She was hospitalized immediately and began an aggressive schedule of treatments, including chemotherapy, radiation, surgeries and a bone marrow transplant. Dani was cancer-free for four months when doctors discovered the disease had returned, this time in her brain.

Despite more chemotherapy and radiation treatments, Dani remained positive and was determined to beat her disease. Dani approached her cancer with the philosophy of "I am living with cancer, not dying from it." Dani demonstrated courage and the will to live by graduating from high school and enrolling in college.

Dani did not fulfill her dream to become a fashion designer. In April 1999, Dani lost her battle with cancer. She was 19 years old.

Dani would often state that *"we're picked for a reason"*, and with that statement in mind, Dani's family and friends established Dani's Foundation, a Colorado non profit organization that is committed to finding the cause and the cure for sarcomas affecting children and young adults.

Since its inception, Dani's Foundation has supported programs and research throughout the nation. Most notably, the Foundation has lent financial support to the research efforts of Dr. Jeffrey Toretsky at the Lombardi Comprehensive Cancer Center at Georgetown University. The Foundation has provided pilot funding to initiate and extend his research on Ewing's Sarcoma.

In 2004, Dr. Toretsky's Lab discovered a key combination of two proteins in Ewing's Sarcoma. By preventing these two proteins from interacting, the scientists believe the effect could be similar to removing the spark plug wires from the spark plugs in a car. Without spark plugs, a car cannot run. Similarly, without this protein interaction, Ewing's Sarcoma cells cannot survive.

Dani's Foundation is dedicated to advancing a global initiative that will be aimed at funding research to find the cause and the cure for sarcomas; funding studies that will target improved treatment protocols for all cancer patients; implementing community education programs that will inform the public on the varieties and symptoms of sarcomas; and continuing to provide valuable resource information to sarcoma patients and medical professionals.

Your support of Dani's Foundation is the key to our ultimate success. We hope that you will join our team - **Dani's Team** - and work with us to offer hope to children and young adults NOW and in the days ahead.



FOUNDATION MILESTONES

Dani's Foundation has provided assistance and leadership via:

1999 - A memorial fund at The Children's Hospital (TCH) in Denver received approximately \$30,000, which was used to fund two Dani's Dine In Kiosks. *Dani's Dine In Kiosks help families and staff order food from nearby restaurants while they are in the hospital.*

2000 - Dani's Foundation awarded \$18,000 to the Denver Cancer Center at The Children's Hospital in Denver for research aimed at Ewing's Sarcoma and other pediatric cancers.

2001 - Dani's Foundation awarded \$20,000 to Dr. Jeffrey Toretsky, at the Lombardi Comprehensive Cancer Center, providing pilot funding to extend his research on Ewing's Sarcoma; \$10,000 to the new Teen Clinic at The Children's Hospital in Denver; \$5,000 to Dr. Edythe Albano's research at The Children's Hospital in Denver; \$1,000 to the Marchello Fund, a scholarship fund for young cancer survivors.

2002 - Dani's Foundation awarded \$5,000 to Dr. Jeffrey Toretsky to extend his research on Ewing's Sarcoma; \$5,000 to Dr. Edythe Albano's research at The Children's Hospital in Denver; \$1,000 to the Marchello Fund.

2003 - Dani's Foundation awarded \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver; \$5,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma; \$2,000 to the Marchello Fund.

2004 - Thanks to funding support from Dani's Foundation, Dr. Jeffrey Toretsky's lab discovered a key combination of two proteins in Ewing's Sarcoma. *By preventing these two proteins from interacting, the research scientists believe the effect could be similar to removing the spark plug wires from the spark plugs in a car: without spark plugs, a car cannot run. Similarly, without this protein interaction, Ewing's Sarcoma cells cannot survive.*

Dani's Foundation has provided funding for Dr. Toretsky's lab to create novel peptides to prevent this interaction.

2004 - Dani's Foundation awarded \$10,000 to Dr. Larry Wiese, at Therapherisis Inc., for research into new treatments for cancer patients; \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver.

2005 - Dani's Foundation awarded \$5,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma.

2006 - Dani's Foundation awarded \$2,500 in funding to The Children's Hospital in Denver for the purchase of new DVD players for all patient rooms in the oncology ward; \$5,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma; \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver; \$1,000 to the Marchello Fund.

2007 - Dani's Foundation awarded \$10,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma; \$5,000 for the continuation of the Teen Clinic at The Children's Hospital in Denver; \$1,000 to the Marchello Fund.

2008 - Dani's Foundation awarded \$10,000 to Dr. Jeffrey Toretsky to continue his research on Ewing's Sarcoma. In addition, Dani's Foundation hired its first full-time Executive Director and hosted the first annual EWS Medical Forum in Denver. This meeting brought together medical and professional advisors, from throughout the nation, to address immediate and long-term research needs that will lead to the eradication of Ewing's Sarcoma and the Ewing's Family of Tumors.

2009—Dani's Foundation awarded \$10,000 to Dr. Jeffrey Toretsky to continue his research on novel treatments for Ewing's Sarcoma. Dani's Foundation was instrumental in organizing the *Ewing's Sarcoma Alliance*, a national Ewing's Sarcoma organization that would bring together specific organizations, foundations, medical practitioners and advocates under an umbrella organization with the goal of working to advocate, educate and collaborate in the campaign to find the cause and the cure for this rare form of cancer. The initial meeting was held in November in Miami and over 40 participants attended and many others enrolled with the hope of working together - as one entity - in the days ahead!

LOOKING AHEAD

PATIENT SUPPORT

Due to the nature of these diseases, pediatric sarcomas are rare and not often seen by pediatricians and family physicians. When Dani was diagnosed, her physicians had to search medical text books in order to offer information on the disease. Patients need immediate access to information and resources.

Dani's Foundation is committed to providing up-to-date information on Ewing's Sarcoma and the other forms of pediatric sarcomas and is working to provide a wide range of resources for patients of all ages.

The Foundation's website offers better access to patients, family members, healthcare professionals and others who are in need of the most current information and age appropriate resources.

In addition to information and resources, Dani's Foundation has been instrumental in developing a Ewing's Sarcoma Alliance that will bring Ewing's groups and professionals from throughout the nation together with the goal of jointly advocating, educating and funding research initiatives that will find the cause and the cure for this dreadful disease. Dani's Foundation, in association with MiNE, LLC, hosted the first ESA meeting in November and signs indicate that this collaborative group will benefit the Ewing's community at large.

EDUCATION

Dani's Foundation is committed to educating the public on the symptoms of Ewing's Sarcoma and the other forms of pediatric sarcomas that are affecting and taking the lives of children and young adults. Dani was mis-diagnosed for almost six months. Could an earlier diagnosis have saved her life? One will never know but, in the event that one child or young adult can be diagnosed and treated earlier, Dani's Foundation developed the Stop, Look & Live education program in 2009 and will work on total Colorado distribution during 2010 to those frontline professionals who deal with our children on a daily basis.

School nurses, coaches, athletic directors and trainers, pediatricians and their nurses will soon be receiving information from Dani's Foundation on the symptoms of pediatric sarcomas with the goal of seeking earlier testing for those unexplained childhood lumps and pains.

By working together, with those at the forefront of childhood health issues, we will hope to offer better outcomes for our future generations.

Dani's
FOUNDATION

RESEARCH

Since its inception, Dani's Foundation has been committed to funding scientific investigation that will assist in finding the cause and the cure for Ewing's Sarcoma and the other forms of pediatric sarcomas that are affecting children and young adults. Funding has been donated annually to local and national pioneers who are seeking to eradicate these horrific diseases.

In addition, Dani's Foundation is committed to working on the development of new and better treatment protocols for all cancer patients. It has been 9 years since Dani Stell's death from Ewing's Sarcoma and still, treatment for these forms of cancers have gone unchanged for over 20 years. Chemotherapy, radiation and surgery are the same for children as they are for adults. Dani's Foundation is calling for the development and implementation of new forms of cancer treatment and the development of age-specific treatments with the goal of offering gentle and effective treatment for children and young adults.

We need your help if we are to raise that *one additional dollar* that will find the cure and lead to the development of more- gentle but effective treatments for our children and young adults.

Won't you join our team...

Dani's Team...

and help us help

those in need of support?

DID YOU KNOW?

- In the United States, cancer is the number 1 killer of children by disease.
- Each year, about 3,000 children die from Cancer - more than from Asthma, Diabetes, Cystic Fibrosis, Congenital Anomalies, and Pediatric AIDS combined.
- Currently, one in every 330 Americans develops cancer during childhood or adolescence, before the age of 20.
- On the average, 46 children and adolescents are diagnosed with cancer every weekday in the United States.
- Nationally, the incidence of cancer in children is more than 20 times greater than the incidence of AIDS in children.
- Pediatric cancer funding is nominal in comparison to other more publicized diseases, such as pediatric AIDS or juvenile diabetes, which increase in awareness each year.
- Awareness of much needed funding for Pediatric Cancer is virtually absent from the public eye due to lack of media attention.
- For example, the funding for pediatric AIDS is four times greater than the funding for pediatric cancer, yet in comparison, twice as many children die of cancer in one month as do die of AIDS in one year.
- The cases of pediatric cancer are increasing at a rate of 1% every year, while funding for research continues to be minimal.
- Cancer during adolescence and young adulthood is increasing and unexplained; progress in treating cancer in these age groups is lagging.
- Sadly, more than 60% of the American public knows little, if any, about pediatric cancer.
- Cancer in childhood occurs regularly, randomly and spares no ethnic group, socioeconomic class, or geographic region.
- A number of the advances in adult cancer treatment are due to breakthroughs in childhood cancer research.
- "The payback for the investment (in childhood cancer) is immense," according to Doctor G. Denman Hammond, Founder of the National Childhood Cancer Foundation. "More value-added can be achieved for every dollar invested in pediatric cancer research than in most if not virtually all other cancer research endeavors".

Statistics from Pediatric Oncology

(http://faculty.weber.edu/jkelly/patho%20223020pediatric_oncology.htm)

2009

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