



**Bennett
Clayton
FOUNDATION**

B C F

For Children with OI

news

from Bennett and his family

volume 5 issue 1

Charity Golf Events



Above: Kaitlyn, Lauren and Cooper, Golf Event 2011
Below right: Bennett tees off, opening the 2012 Charity Golf Event

BCF Charity Golf Events continue to be held early in August at Shoreland Country Club. Each year we welcome new golfers as well as friends and sponsors who have been with us at some or all nine of our tournaments. The 2011 theme was a "Western" one; in 2012 we celebrated a U.S. Olympic theme. Games and prizes continue to be a highlight of each event. In 2011, a trip to Woodside Ranch and Resort was the Grand Prize, awarded to Shawn Johnson. Thanks to Chuck and Peggy Gappa, a real buckboard set the scene for our western theme. Hats, boots and bandanas were the attire of the day.

The mission of the Bennett Clayton Foundation for Children with OI is to raise funds for education, research and support for issues affecting children with Osteogenesis Imperfecta.



Because the date of the 2012 event coincided with the "real" Olympics, it was a red, white and blue day! Many silent auction items and golf prizes reflected a patriotic theme. An autographed swimsuit donated by American diver, Kelci Bryant was a special gift. Kelci won a silver medal for the U.S. Her swimsuit, framed and preserved by Wayne Schmidt of Photo Shop Studio, will be a treasured addition to the home of the lucky family who had the highest bid! Our own



medal winners for the day (pictured above) were Matt Brower, Mark Noack, Mike Wolle and Brent Schafer. The Grand Prize of a kayak was won by Kevin Frank, who will now begin practicing for the 2016 Summer Olympics!!

Paperless?

Would you like to receive this newsletter electronically? If so, please send us a note at BCFforOI@aol.com.

Thank You!

...to our
2012 Sponsors,
including:

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The OI Foundation

Conference: The biennial conference of the national OI Foundation was held once again in a suburb of Washington, D.C. in July. Five members of the DeBlieck/Coomer families traveled there for the three day meeting. We attended sessions concerning research, exercise pertinent to OI patients, the ongoing discussion regarding the use of bisphosphonates, as well as many other events and educational opportunities related to patients with Osteogenesis Imperfecta. The Bennett Clayton Foundation also provided financial support for five families from our area to attend the conference.



Brenda DeBlieck, Erin DeBlieck, Marianna and Bennett at the 2012 OI Conference.



Minnesota Friends at the OI Conference

Research: The Bennett Clayton Foundation continues to meet its annual commitment to the OI Foundation in support of the Linked Clinical Research Clinics. According to the OI Foundation, LCRC are a nationwide network designed to provide the highest-quality of standardized medical care for people living with Osteogenesis Imperfecta. All of the LCRC sites have a multidisciplinary group of specialists with extensive experience caring for children who have OI. In addition to providing high-quality standardized care, the LCRCs, through a coordinated effort, will aim to advance standards of care and improve treatment through clinical research. By sharing data, the Centers will be capable of tracking how OI changes across a lifetime, what complications are common, and which treatments are beneficial.

OSTEOGENESIS IMPERFECTA Over the past nine years, BCF has given over \$100,000 to the OI Foundation toward continuing their efforts in research and awareness of OI. ■

OI FOUNDATION *The mission of the Osteogenesis Imperfecta Foundation is to improve the quality of life for people with OI through research to find treatments and a cure, education, awareness, and mutual support. To learn more, visit www.oif.org, e-mail Bonelink@oif.org, or phone 1-800-981-BONE.*

Gifts from Others

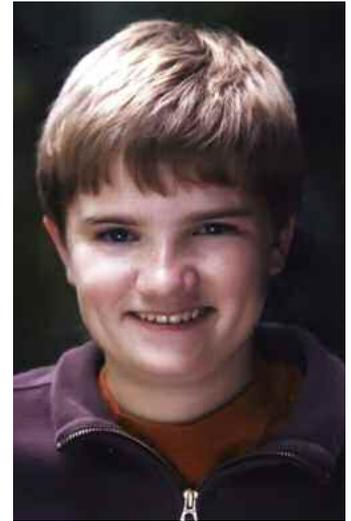
An anonymous donor gave the Foundation \$300 to be distributed to families of our choice at Christmas, 2011. As directors, we decided to match that gift and selected three families who then received \$200 each as an early Christmas gift. Once again, our hearts are warmed by the generous giving of many, many people who support the Bennett Clayton Foundation for Children with OI. ■

BCF Scholarships

The winner of our first Bennett Clayton Foundation scholarship, Tawnya Taylor, will soon graduate from Kaplan University. Hanna Rapsky continues to study at University of Wisconsin–Stevens Point. Felicia Wagner is a student at the University of Minnesota and Alex Harrison is studying at Wartburg College. Application materials can be found on our website, www.BCFforOI.org. Administered by Scholarship America, BCF scholarships are open to post-secondary students with OI in Minnesota, Wisconsin, Iowa, North & South Dakota. To date, the Bennett Clayton Foundation has awarded \$20,000 in student scholarships. ■



Felicia Wagner



Alex Harrison

Others Helping...



Left: 2012 Wells Fargo Charity Golf Event

Right: Kevin and Steve Traut of California's Superior Press with the DeBlieck/Coomer family.

The WITS (Worldwide Internet Treasury Services) division of Wells Fargo Bank held 2011 and 2012 events at Prestwick Golf Club in Woodbury. These annual events provide significant support to the Bennett Clayton Foundation. The DeBlieck and Coomer families assist with the day's events and meet golfers on the course to share information about BCF and OI. Friendships have been formed with Wells Fargo employees and vendor-sponsors from throughout the United States and Canada. Proceeds from these events are shared by The Bennett Clayton Foundation, The American Cancer Society and Vail Place.



Cellist, Jeffrey Erbland and Friends

Jeffrey Erbland, a member of our OI community, and several friends from the Minneapolis area performed in concert on May 6, 2012. Held at Olivet Congregational Church in St. Paul, the accomplished musicians shared chamber music of Bach, Shostakovich, Davidov, Shaporin and Schubert. Proceeds from the performance were donated to the Bennett Clayton Foundation. ■

Personal Health Grant

Personal Health Grants are awarded following June 30th and December 31st deadlines each year. The Foundation is pleased to have continued its support of children and their families by funding special accommodations in a home and also with necessary medical expenses. To date we have been able to give \$17,000 in grant awards to area families. Children with OI are encouraged to apply for funding assistance with medical needs not met by families' insurance, personal funds or other aid resources. Information and an application form can be found on our website. ■

Watch For

...Spring concert to benefit the BCF Scholarship Fund by St. Peter's local jazz group, The Riverlights. Details will be posted at www.BCFforOI.org and on our Facebook page.

Meeting Friends

One of the most rewarding experiences for us is to facilitate gatherings of families and friends affected by Osteogenesis Imperfecta. To meet new people and to share experiences, challenges and opportunities is one of the Foundation's important goals. The Brundieck/Schiltz families continue to help us in coordinating these events. Three years ago, Carol Brundieck organized a gathering at the Thompson Park Activity Center in West St. Paul. Last fall, her brother, Bob Schiltz, organized a Sunday afternoon event at his church in Richfield. They were assisted by Carol's husband, Lane and their parents, Joe and Judy Schiltz. We are grateful for their participation.



In response to suggestions at earlier gatherings, BCF invited Dr. David Vernick (left) to be our guest at the October, 2011 gathering. Dr. Vernick is the leading authority in the nation on hearing loss in OI patients. He is an Assistant Clinical Professor of Otology and Laryngology

at Harvard University and serves on the medical advisory board of the national OI Foundation. His presentation provided clinical information as well as hope for those present who are suffering from hearing loss due to their OI. We were truly honored that Dr. Vernick would travel to Minnesota to share his expertise with us.

Then in March of 2012, Carol and Lane organized a bowling event at the Brunswick Zone in Lakeville, Minn. Once again, those in attendance thoroughly enjoyed their time together—playing, eating and sharing their OI experiences.

Our Next Gathering: All OI friends are invited to join us for our fall "Meet & Greet" on Sunday, October 28th at the Southdale YMCA from 2 to 4 p.m. In an informal setting, share information or experiences, meet new friends, frost your own pumpkin cookie, decorate real pumpkins, bob for apples without water and more. Fun for all ages. Please contact us at BCFforOI@aol.com for more information or to let us know you can join us. ■

Bennett...



...is in 5th grade at North Intermediate School

...loves to read, especially books by his favorite author, Gary Paulson



...cares for his dog, Luigi



...enjoys hunting, fishing, golfing, baseball, and snowmobiling (when there is snow!) ■

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