



A Special Report for Our Awareness Day Advocates!

Thanks to all of you who led the way in launching our first PC Awareness Day effort! We wanted to share with you the photos and words of the many Awareness Day volunteers. We were overwhelmed with the enthusiasm and emotion of the Day! Some of you were also able to raise money for PC research and patient support and we give you our special thanks. Following are photos and quotes from organizers who have reported their events to PC Project as of 21 June 2012. If your event is not listed, please send the information and we will continue to update this file which is available on our website.



Christine & Matthew Block and Family
Rothschild, Wisconsin, USA

“It was a great experience. There were 810 mountain bike racers and many were generous buying baked goods and donating. We were able to educate many about PC! We had over 20 friends and family bake things and many friends volunteered to help over the weekend.”



Jo Brodie and Family
Wellington, New Zealand

What a weekend! I had so much fun and was stressed out. So pleased that this awareness day has raised a massive awareness worldwide and hopefully a lot of money - yah!!!! I truly had so much fun and wee Flynn enjoyed it too - although he didn't want to go in a hot rod as I think he thought he was leaving the party :) A few folk / companies have been mentioning that they are looking for charities so you never know, Flynn may become a charity for someone and all proceeds raised will come to you. **Awareness is definitely out there now :)**



Marie Catanese
Estero, Florida, USA

A friend of the McGrath and Filoso families, Marie gives monthly donations to support PC research. For PC Awareness Day, she held a yard sale and pizza party. As she wasn't satisfied with the results, she has now contracted to sell chocolates with 50% of the profit to PC Project.





Sylvie and Chistopher Cierpucha
Loyon, France

"For June 2, we sold 419 balloons, it's incredible. This day was a great success in human solidarity."

Francois Cierpurcha is French National Archery champion and provided archery instruction.



Russell and Linda Clark
Lewiston, Utah, USA

The Clarks had a marvelous idea for PC Awareness Day and saved their coins over the six months since the project was announced and had a wonderful donation for PC Awareness Day.



Monica Costa & Carlos Ramos Family
Rio de Janeiro, Brazil

Celebrated PC Awareness Day by having dinner with family and friends and raising funds for a donation.

Gina & Jason Defebaugh Family
Clinton, Illinois, USA

Last weekend, a very special woman participated in a mini-triathlon. She completed a 1/4 mile swim, 12 mile bike route, and 3 mile run all for my daughter and for PC!! She raised \$230 in donations for PC and still has more to come! This was her first triathlon and she did a wonderful job. I was so moved by her generosity and kindness that I knew you would be too. What really got me is when she put her shirt on before her bike route with the PC logo on front, and the words "I swim, bike, run for Rylee". It made me overwhelmed with emotion. She did a lot of research on the website before the triathlon. I believe Rylee has captured her heart as well.



Tina Greenaway
Royston, England

Tina donated a portion of all sales received from her online store on 2 June.



Jeannette Howell and Family
Poole, England

The Howell Family raised awareness and funds by placing donation tins and fliers in local restaurants.

Katri-Anna Lehto
Nousiainen, Finland

Katri-Anna wrote a PC-related post on her Facebook page every day for a week, and she distributed PC Awareness brochures. In addition, she traveled to meet another PC family in Finland.



Graham Long
Billericay, England

As a London cabbie, Graham spread PC awareness by sharing brochures with others in order to create a sense of connectedness within the community.



Jennifer Marcinko
Sykesville, Maryland, USA

Jennifer's son played in a softball game in honor of PC Awareness Day. Jennifer also wrote a wonderful email to her friends for PC awareness.

Soe Mattijssen and Family
AV Oosterbek, Netherlands

The Mattijssen Family celebrated PC Awareness Day by hosting a house party, and various items were sold to raise funds. "Many friends, relatives and neighbors came to us. The weather was excellent, so we could stand outside in the sun. There are still a lot off commitments and the 16 off June there is a celebration party in our street. All the guests will donate for our PC project." www.pachyonychia.nl



Roseann and Mike McGrath Family
King of Prussia, Pennsylvania, USA



The McGraths and Roseann's parents, Nicholas and Joan Filosa, participated in PC awareness day with a yard sale, a hair salon raffle and other events. Roseann also sent letters to their friends and family requesting support with excellent response.



Re: June 2 PC-Awareness Day Yard Sale

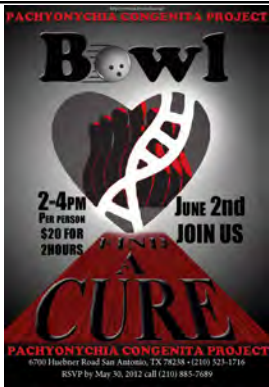
What a rainy day it turned out to be, but that didn't stop David and I from making the best of our fund raiser/ yard sale. I was one proud Mama! I sat and watched my son hand brochures out to people coming to look around. When they asked questions, he answered them. If my Grandmother was still alive she would be so proud to know how far we've come. No longer are we sitting on fingers at the dinner table, hiding our PC, as she did...instead we are sharing with the anyone who stopped by the information about PC. Proud that we have an organization that stands by us, most importantly we are not the only ones with PC...it may be rare...but we have met friends with it too. (Thanks to last year's PC Convention) We are not alone!!

My Mom came and sat with us too. She enjoyed the time spending with me and her grandson. We enjoyed her time as well. I even had a wonderful neighbor, who I met for the first time, donate some items for me to sell. She was very interested in the rare condition. Overall I believe the yard sale was a success. I raised more money that I anticipated with the weather conditions being so poor.

Jessica Mortier Family
Lagrangeville, New York, USA



Sincerely,



Adam and Ariel Rocha Family
San Antonio, Texas, USA

It started out as a school project - but since PC is real, the Rocha's decided to actually do an event. They had a lot of support from the school neighbors for their Bowl-for-a-Cure fundraiser event on June 2nd at the Bandera Bowling Alley. PC pamphlets were handed out the day of the event and a nice amount raised.



Janice Schwartz and Family
Salt Lake City, Utah, USA

"We were thrilled to be part of this worldwide effort where everyone can think about PC on this special day. We had so many donations and so many volunteers to help—we raised more than we had hoped and gave out lots of brochures."

Shareem & Raj Sharda
Toronto, Canada

The Sharda Family sent this wonderful email to family and friends and received excellent responses and donations. "The Pachyonychia Congenita (PC) Project has marked today, June 2nd, as PC Awareness Day. Individuals across the globe who are involved with the PC project are spreading this awareness in a variety of ways. We wanted to do so by just saying a big Thank You for your support. Since the time of our daughter's diagnosis, you have supported us with encouraging words, advice, referrals, donations and most of all prayers and love.

The PC project has been a great resource for us, providing great advice and telephone consultations as needed. We have sent many pictures of Shyla's manifestations to them which is also helping in their research as she is the youngest patient registered with the project."

Harry, Amanda, Savannah Stergar and Family
Indianapolis, Indiana, USA

The Stergar Family held a car wash event to raise funds and awareness. Furthermore, the event entailed a balloon release, food, music and the handing out of informative brochures.

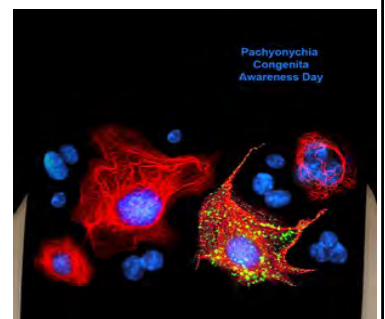


Following the event, the family and PC Project were interviewed by KLOVE radio station about PC. The interview was aired on June 16 and may be aired nationally. A link to the interview is on the PC website.

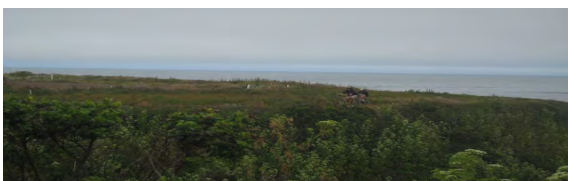


TransDerm—ThickSkin Duathlon
Santa Cruz, California, USA

Even those who are researching PC and trying to find treatments and a cure participated in PC Awareness Day. The TransDerm team organized the ThickSkin Duathlon (Run, Bike, Run) which was a huge fund raising success. PC patients including seven members of the Jiang Family, Esteban Abarca, Stephen and Amy Wittmer and Charles Merrill attended and helped to man the PC information booth at the event.

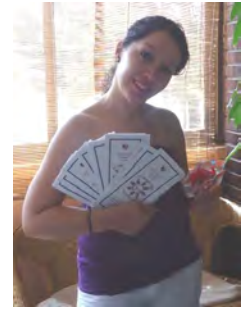


The snazzy black tee-shirts feature images of PC skin cells! A few are still available. To order, contact PC Project.



Pamela Triguero
 Mejorada del Campo (Madrid), Spain

"I have distributed leaflets translated into Spanish with a lollipop. No one turned me down! I always liked the phrase, "long after the storm comes the calm," that is what I think when I am in pain and I know the next day will be better. I want to share with all of you and give you encouragement and hope because I am convinced that you will find a cure for all. My heartfelt thanks."



Elise van der Laan-Kokx and Family
 Liempde, The Netherlands

"We have had a great and very busy time with all our PC Awareness Day activities. We have had a wonderful family dinner, a family auction, we have been flyering in our town and in a neighbor town, we stand on markets, we sold bird houses in the form of a wooden shoes and we have eaten pancakes on 2 June. More activities are in progress. for an impression you can look at our website at <http://www.pc2012helpian.nl/> "



aan verkoopt vogelhuisjes om geld in te zamelen voor de ontwikkeling van medicatie om wgenen. Haar zoonje lin tijdt aan deze aandiening. (Foto: Gerard Schalks).

COMING SOON.....

Pachyonychie Congénitale
 maladie génétique rare, douloureuse et invalidante

A Sarrebourg, Samedi 16 juin 2012:

- stands au Marché aux livres d'occasion à la Bibliothèque Municipale (dès 10h)
- tournoi d'échecs au centre socioculturel (dès 13h) pour soutenir la

1^{ère} journée mondiale de sensibilisation
 ayant lieu le 2 juin

Douleur permanente – hyperkératose palmo-plantaire – ongles épais

Association Le Cœur au Pied. Contact: Béatrice Wannenmacher: 05 25 75 88 11 ou 03 67 23 07 12.



THE FAMILY AND FRIENDS CHARITY SOFTBALL TOURNAMENT

To benefit **PACHYONYCHIA CONGENITA PROJECT**

Date: JUNE 23, 2012
 Time: 9:30 AM (FIRST GAME WILL BEGIN AT 10:00 AM SHARP)

Location: HILLMAN FIELD IN EMERSON
 Donation: \$3.00 PER PERSON

Players include local Police Officers and Firefighters and some of our finest coaches in town.

There will be a raffle items, bounce house, face paint, beverages and refreshments available for purchase.
 Bring the kids for lots fun and food!

Come rain or shine!!!!

TOWN FIREWORKS will follow the championship game.

COME OUT & GIVE YOUR SUPPORT TO NICOLE SMITH & PC PROJECT