Starting the New Year Strong!

Because of you, 2021 is already turning out to be a year of hope and continued progress. Despite the global pandemic, the success of the year-end campaigns, your sustaining monthly donations, along with your never-ending support in multiple ways throughout the past year have kept PC Project financially solvent and organizationally strong. With our team of scientists, physicians and industry partners, we continue to work for what one PCer recently expressed hope for: “A chance to walk barefoot in the grass.”

PC Project’s MSAB Meeting

On February 12, members of PC Project’s Medical and Scientific Advisory Board (MSAB) met under the leadership of Professor Eli Sprecher to discuss research priorities and advise PC Project on how to best move PC-related research forward.

Wes Kaupinen, CEO of Palvella and Braham Shroot, CSO of Palvella, joined the meeting to present data about the VALO clinical trial to the MSAB.

In the spirit of collaboration, this remarkable group of scientists and clinicians guides PC Project and has begun the planning of the 2021 International PC Consortium (IPCC) Symposium where scientists, physicians, and industry partners will meet virtually to discuss PC research. The best part about these experts is they genuinely care about PCers and we’re extremely blessed to have them on our team.

PC Scientist Honored for Commitment to Rare Diseases

Congratulations to Alain Hovnanian, who is the recipient of the Eurordis Black Pearl Scientific Award for 2021. Professor Hovnanian is not only a fabulous scientist and clinician but a true friend to PC Project and PC patients.
“The EURORDIS Scientific Award recognises Prof. Alain Hovnanian’s scientific excellence and comprehensive reach, the outstanding dedication he has demonstrated in the rare disease community and the positive impact he has made on rare disease research and patient community.

His research and work in rare skin diseases has proven ground breaking, particularly with Epidermolysis Bullosa and Pachyonychia Congenita, both in France and at international level.”

Here are additional details:

Seeking Participants for Pachyonychia Congenita Clinical Research Trial

If you (or someone you know) has PC with a KRT6c or KRT17 genotyped mutation, you may be interested in participating in a Phase 3b clinical research trial for an experimental therapy that is applied to the soles of your feet.

Some of the requirements for participation include:

- Must be able to utilize telehealth to attend study visits.
- Given the ongoing pandemic, there will be flexibility with travel requirements.
- Must be at least 18 years of age or older.
- Have a clinical diagnosis of PC, genetically confirmed to involve one of two keratin genes KRT6C or KRT17.
- If you have not been genetically tested, or if you do not have a copy of your genetic testing report, please contact PC Project at study@pachyonychia.org for more information about genetic testing.
- If you know your mutation because a family member was tested, you will need to do a confirming test through PC Project, so you will have your own report.
- Have not participated in a clinical research study in the past sixty days.
- On a daily basis during the study answer questions on a smartphone-based app.

Participants must be, in the opinion of the study doctor, able to understand the study, and cooperate with the study procedures. Your participation is voluntary.

If you qualify for study participation, you will be compensated for your time and your travel expenses to and from the clinic for you and a companion will be covered.

You can find more information about the study and participating sites on www.clinicaltrials.gov.

If you are interested in participating, you can either complete the interested form at https://www.surveygizmo.com/s3/5392214/VALO-2
**Growing Globally**

Physicians and patients from all over the world continue to reach out to PC Project for guidance and diagnostic and clinical help. In 2020, we had 111 new patients join the International PC Research Registry (IPCRR). For example, Dr. Sandra Milena Ceron Narvaez, from the University of Cauca in Colombia, recently helped register six of her patients and collected their saliva samples for genetic testing. We welcome all six of these beautiful people (seen in the photo above) from Colombia to the global PC community!

As more and more patients join the registry from various countries all over the world, PC Project is grateful to members of the PC community who have helped with translations and who help welcome patients in their own language.

One such place for patients and their loved ones to receive encouragement and connection is the Pachyonychia Congenita Patient Chat, a private Facebook group for those in the registry: https://www.facebook.com/groups/pachyonychia

If you wish to connect with others in your own language, join this Facebook group and post in the language of your choice. You will find friendly, helpful PCers to talk with, who will share tips, thoughts and feelings about living with this rare disease.
Painting for PC

Often, we with PC are afraid or embarrassed to tell others about our PC. Or maybe we simply want to be seen as “normal”. But because one of our PC families was willing to tell their neighbor and friend, Greg Krugel, about PC, not only did Greg learn about PC, he has become an advocate and friend to PC patients everywhere. You may recall some of his artwork, featured in past news briefs, that he created and sold to support PC research.

Here is Greg with his buddy, Wyatt (who has PC), with Wyatt’s mom, Jen, and big sister, Madison.

I’m happy to announce that as the result of this effort and that of Wyatt’s family and our family and friends, I am sending PC Project a check today for $380.00 which I have discovered will be matched 2-for-1 raising our donation value to $1,180.00!

For those of you who may be interested in this condition or the PC Project as a charity organization, here is a link to their year-end newsletter, a monthly publication that is sometimes touching but always educational and informative regarding PC.

Thanks to all of you who expressed your admiration and respect for my sidewalk chalk portrait of our little pal. I hope you find the newsletter interesting and informative.

Thanks to Greg for advocating for PC, and to the Rocha family for letting others know how PC affects your family!

In Memory of PCer Fran Sargianis

Our hearts go out to the family and friends of Fran Sargianis, not only a PC patient, but a lovely person who attended a number of Patient Support Meetings with her sister, Mary Howard. Fran passed away on January 27, 2021, at home with her family by her side, after valiantly fighting cancer for over three years. We pray for peace and comfort for Fran’s family and loved ones.

Facebook Birthday Fundraiser

A huge thank you and happy birthday to Edward Pyner, for creating a Facebook fundraiser for his birthday to raise awareness and funds to support the mission of PC Project. We are grateful to each of you for finding your own ways to support PC Project.