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2011 Annual Report

Mission Statement

PXE International initiates, conducts and funds research on pseudoxanthoma elasticum (PXE), educates clinicians and supports affected individuals.

Introduction

PXE International has had an incredible year. Now completing our 16th year of existence, we are constantly on the road toward a treatment for this condition. With exciting developments in drug research there is the very real chance that a child diagnosed today would never face the reality of vision loss, and those with symptoms have already been able to mitigate the worst outcomes. This is the most exciting time in our organization's history since we found the gene in 2000. Along with this exciting new research, we have also increased our patient support network holding six regional meetings in four countries in 2011. This coming year we will be holding our professional research meeting as well as our 9th Biennial Patient Conference in September of 2012.

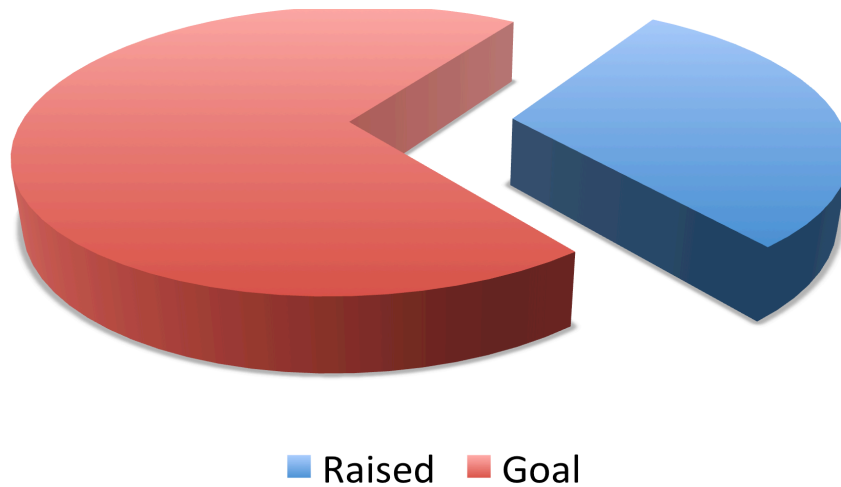
One of the roadblocks toward access to treatment is the cost of further research. As it currently stands, it would cost around 2.5 million dollars to fund all the areas of interest that our collaborating scientists have proposed. Grant requests are submitted to us often and we are faced with the difficult choice of where to place our limited funds.

With the economy lagging, funding for rare disease research is difficult and sometimes impossible to find. Public and private agencies have begun prioritizing their missions and often smaller organizations and disease groups drop off the list. This leaves the personal connections we all have to each other. Funding multimillion-dollar scientific research from donations of \$2, \$5, \$20, and even \$500 is a daunting task. But with your amazing generosity, and whatever you have found in your hearts to give, we have come an incredible distance.

It has always been the task of the few to fight the good fight. We at PXE International champion every individual who visits our donation page, writes a check, donates their medical records or fills out an online questionnaire in our Epidemiological Study. Each one of those actions moves us closer to our collective goal to make living with PXE an experience free of hardship.

PXE Research

Last year we announced our intention to raise 1.5 million dollars for research in just 5 years – the 15th Anniversary Challenge. We knew it would be a tough mission to complete. Now we are just over a year into the challenge and that means it would be great if we could have raised 1/5th of the challenge goal. Together with us, you have all raised over \$450,000! An amazing feat and almost 1/3rd of the entire amount. This is a testament to the unending support of the wonderful people who suffer daily at the hands of this disorder. Let's not stop now! We must keep the momentum going and make sure we can truly invest in the best science and research possible around the world.



2011 Accomplishments

Completed rebranding of organization in print and online with new logo and website

Increased the level of activity and awareness by utilizing social media and a more comprehensive website

Held regional meetings in four countries

Published two MicroMemberGrams and one Fall MemberGram

Raised almost 1/3rd of our anniversary challenge – ahead of schedule!

Conducted the beginnings of our massive Epidemiological Study

2012 Goals

Hold more regional meetings around the world

Publish MicroMemberGrams, MemberGrams, eNews, Webinars, and other media

Increase our international presence and resource lists

Plan and conduct two back-to-back conferences

Fundraise and fund as much research as possible
