



# Pachyonychia Congenita Project

*Fighting for a cure. Connecting & helping patients. Empowering research.*

## PC Advocates Training Session 3

# Telling Your PC Story

- How does PC impact your life?
  - The burden of PC
- What is the hardest thing about PC?
  - The burden of 'rare'
- How does PC Project help you?
- How do you manage/cope with PC ?



# Speak to your audience

- Who is your audience?
  - Other patients
  - Interested professionals
  - Physicians/Scientists
  - Donors
- An advocate needs to have a very short, impactful message that can be tailored to each audience



# Telling Your PC Story

**The most effective way to make these points real is to illustrate points with short personal stories from yourself or others.**

**Fewer words = more impact**



# The Burden of PC

- **Rare Disease**

- Misdiagnosis and misunderstanding
- No treatment (unmet medical need)
- Isolation (value of PC Project)

- **Pachyonychia Congenita**

- Pain
- Appearance
- Time for care

# The Burden of PC

## Rare Disease

### Misdiagnosis and misunderstanding

*“I have been with my daughter today at the dermatology doctor. It was purely ridiculous. The doctor sat and said to our faces that he never has seen anything like it...”*



# The Burden of PC

## Rare Disease

### **Misdiagnosis and misunderstanding**

*“I was diagnosed with several different diseases before I found PC Project. It wasn't until I started trying to find an organization dedicated to ‘Palmer Plantar Keratosis of Vorner’ that I was referred to PC Project. I went through testing and it turned out I actually have PC!”*



# The Burden of PC

Rare Disease

**No treatment (unmet medical need)**

*“I am 42 years old and have spent years going to dermatologists, podiatrists, disease specialists, etc. without success. I have been treated over the years for thrush, fibromalgia, arthritis, viruses, infections, pain, restless leg syndrome, and depression. I have had biopsies taken from my mouth, tried various medications, etc.”*



# The Burden of PC

Rare Disease

**No treatment (unmet medical need)**

*“I am nineteen years old but I wasn’t diagnosed with PC till about two years ago. I went to a lot of doctors to find out what I had but they told me they didn’t know what I had or they gave me a false diagnosis... I was pretty excited to find out what I had but mad that there wasn’t a cure.”*



# The Burden of PC

- Rare Disease
  - Misdiagnosis and misunderstanding
  - No treatment (unmet medical need)
  - **Isolation** (value of PC Project)
- Pachyonychia Congenita
  - Pain
  - Appearance
  - Time for care



# The Burden of Rare

Rare Disease

**Isolation**

My daughter found information about this project and for the first time, we had hope.



# The Burden of PC

Rare Disease

**Isolation**

*“For the first time in my life, I feel hope. Hope because now I know I am not alone in living with this disease, and hope that one day, there will be a cure for PC.”*



# The Burden of PC

- Rare Disease
  - Misdiagnosis and misunderstanding
  - No treatment (unmet medical need)
  - Isolation (value of PC Project)
- Pachyonychia Congenita
  - Pain
  - Appearance
  - Time for care

# The Burden of PC

## About Pachyonychia Congenita Pain

*“Sometimes I have to hold my breath when I get out of bed because I know the first 5-6 steps are going to be really bad... I have been told just get some insoles. I have been advised to get better sneakers, loose weight. My husband thinks I am faking it...”*



# The Burden of Rare

## About Pachyonychia Congenita Pain

*“My feet hurt all the time. I am asked by various people if I am limping. The doctors don't understand the pain and limit pain medications for just "callouses". It is difficult to say that you are in pain, but have no diagnosis to prove what you have.”*



# The Burden of PC

*“ I was born with thick nails, and calluses and blisters formed as soon as I learned to walk. I basically started crawling again, once I learned to walk because of the pain. I would love to see an effective PC treatment more for the kids than for me - but I wouldn't mind walking pain free either.”*





# The Burden of PC

## About Pachyonychia Congenita Pain

*Its always been really painful and I have tried a lot of things to help it. It's now affecting me more because I started a new job where I'm on my feet... the blisters are coming back worse and making it extremely painful to work.*



# The Burden of PC

- Rare Disease
  - Misdiagnosis and misunderstanding
  - No treatment (unmet medical need)
  - **Isolation**
- Pachyonychia Congenita
  - Pain
  - **Appearance**
  - Time for care



# The Burden of PC

## About Pachyonychia Congenita Appearance

*“Sometimes people run away and think I’m gross just because I have PC...I feel sad and lonely...” (age 8)*



# The Burden of PC

## About Pachyonychia Congenita Appearance

*Living with PC has been very difficult for me. I was always made fun of for it and everybody thought it was something I could help.*



# The Burden of Rare

## About Pachyonychia Congenita Appearance

*“I have spent my life dealing with this condition. I developed callouses on my feet as soon as I started walking. I was made fun of early in life in swimming class because of my feet and have been embarrassed to show my feet to anyone since.”*



# The Burden of Rare

## About Pachyonychia Congenita

### **Time for Care**

I scrape the callouses regularly and file down my thickened toenails, but they never pass for normal.



# The Overall Burden of PC

- Rare Disease
  - Misdiagnosis and misunderstanding
  - No treatment (unmet medical need)
  - Isolation (value of PC Project)
- Pachyonychia Congenita
  - Pain (limiting activities)
  - Appearance (a visual disorder)
  - Time for care



# Advocate Training and Tools

- ASSIGNMENT

Write and practice telling your story

- **Next web meeting we'll share stories**
  - **2 minutes each (about 300 words or less)**
- Next web meeting we'll use the PC website together





# Advocate Training and Tools

- 4th training session—each person will have 2 minutes to tell their PC story
- In-person training

