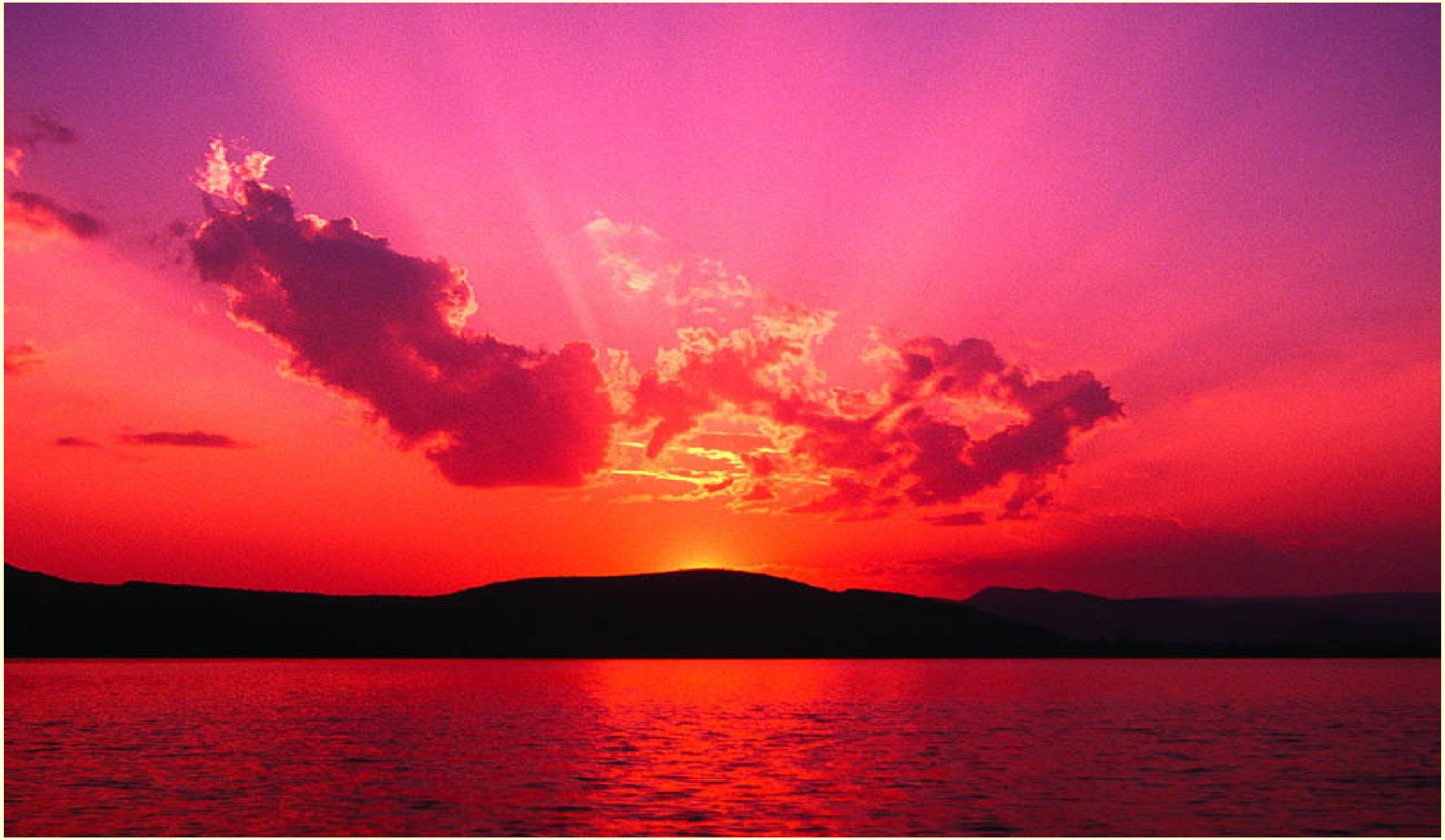
Psycho-social Aspects of People Affected by Rare Disorders (Specifically FOP & POH)



OUR story is different from the very first moment of diagnosis

- No set protocol
- No therapies, no waiting rooms & few doctor visits
- No *immediate* hope
- We go home with few answers

The FOP & POH diagnosis feels like a wave crashing down on the family

FOP & POH Families and others with rare conditions

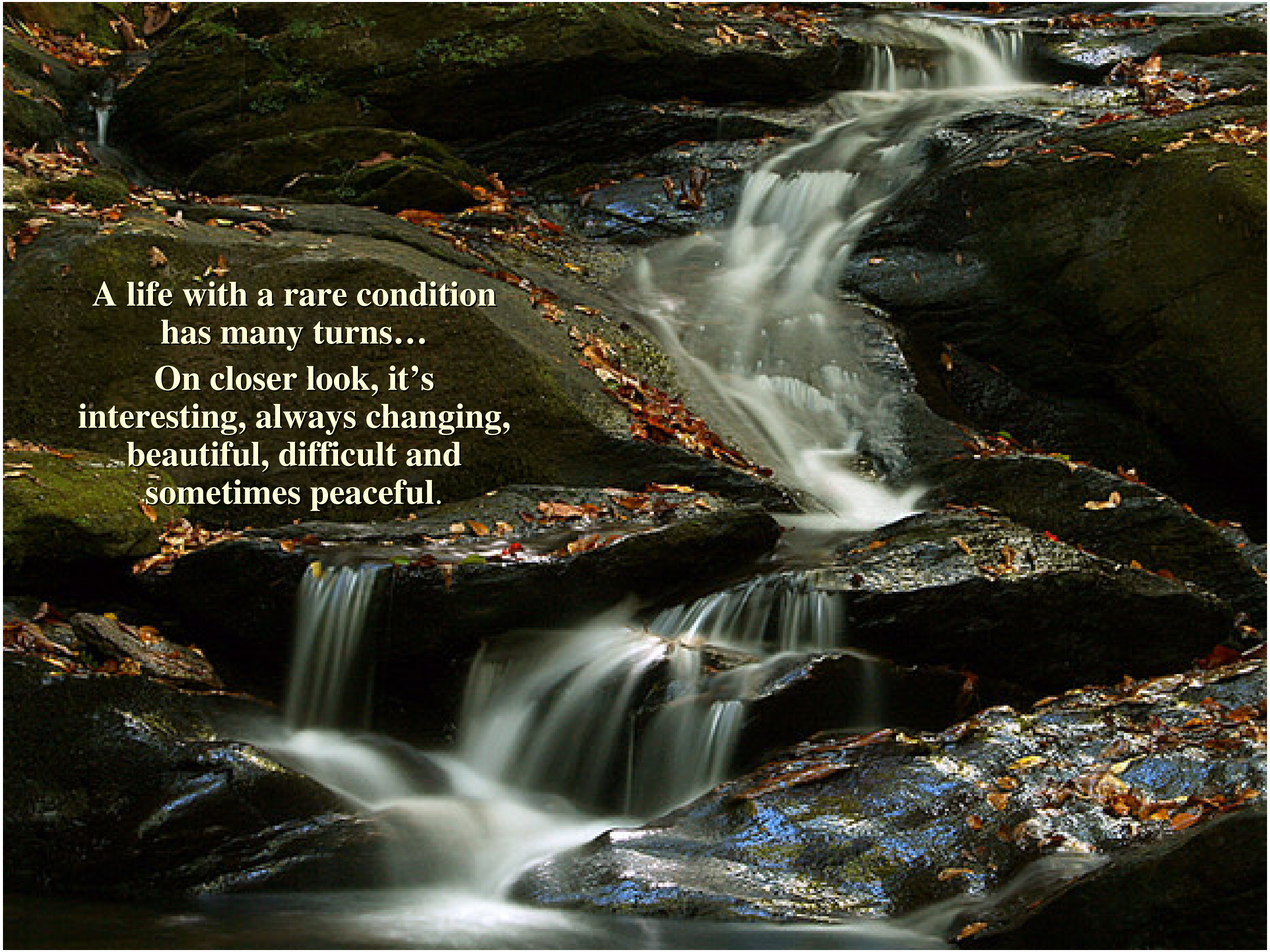
- Feel isolated by the rarity of the disease
- Often feel helpless to take action to combat the problems that our loved ones have
- Frequently we are the only ones identified with such a condition in our family & communities
- We face the challenge to educate everyone we meet about FOP or POH in order to be understood

Most children with progressive rare conditions

- Have a maturity about them
- Have great determination to overcome hardships
- Establish an intensity in order to survive
- Have a need for “hope”
- Have a need for control
- Often do not want “extra attention” as they already receive more than the norm
- Have more experience interacting with adults, medical professionals and people caring for them
- Sensitive to their bodies and overall health
- Strong sense of humor

Stress of progressive condtions

- Challenges the family unit to communicate and resolve issues
- It can be exhausting work to care for someone in need of long term care
- Challenges families to keep on living a full life
- Puts stress on a marriage & relationships
- Requires patience and understanding from siblings, family and friends



A life with a rare condition
has many turns…
On closer look, it's
interesting, always changing,
beautiful, difficult and
sometimes peaceful.

The challenges can empower us….

- To be managers from the very start of our life with a rare disorder
- We learn to reach out to people that we may never meet in person for solutions to daily living issues
- We work *with* our doctors to find solutions to our children's discomfort & challenges
- We face obstacles in everyday living that can not be easily solved by professionals

When parenting a child with a rare disorder:

- You become a *medical technician* that manages every day medical issues & concerns, making tough decisions in what is sometimes an uncertain path
- You are forever an *ambassador of HOPE* for your child, your family, your extended family and your community
- You are a *teacher* about a different kind of life for all of those that do not understand or relate to FOP or POH
- You're forced to become an *information engineer* ready to teach the uneducated about a condition that few others know about or can even begin to imagine
- Resulting in an *expertise in the psychology of life*

The Rarity Alone Creates Opportunities

There are many opportunities to participate in making a transformation…

to “make a difference”…

in the world around us and in the lives of people with FOP & POH.

We are the lucky ones…

Very few orphan diseases (rare disorders) have the attention of anyone in research.

POH & FOP have the devotion of a world class reach team dedicated not only in *effort* but also in *heart,* to finding a treatment and a cure for the people with POH & FOP.

- With 75% of funds coming from families
- A talented international collaboration

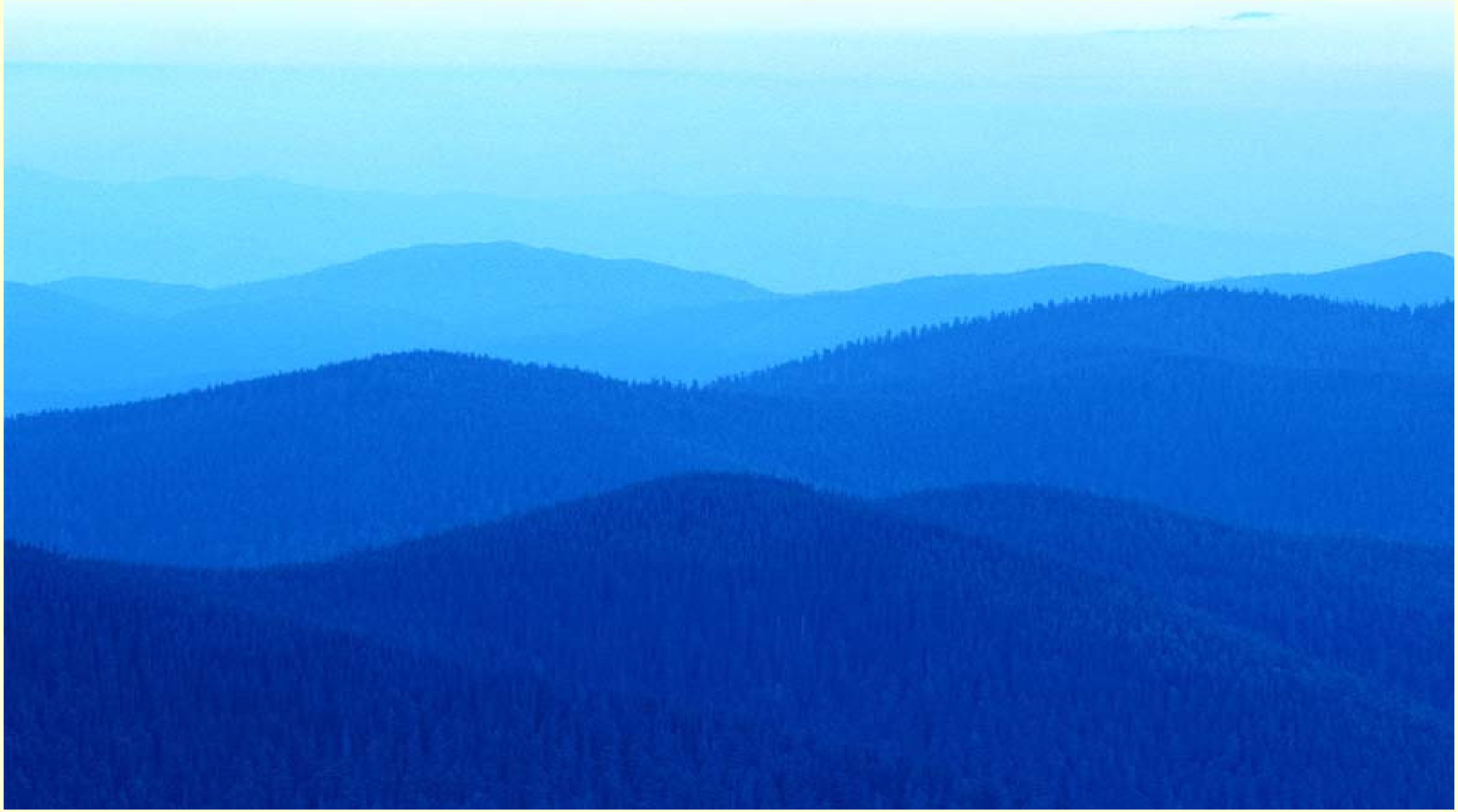
This Generation of FOP & POH Families have changed history

I wonder what it is about this generation of people with FOP & POH

that they took action to…

- Fund medical research
- Organize themselves and host meetings
- Develop web sites
- Write books
- Participate in media coverage

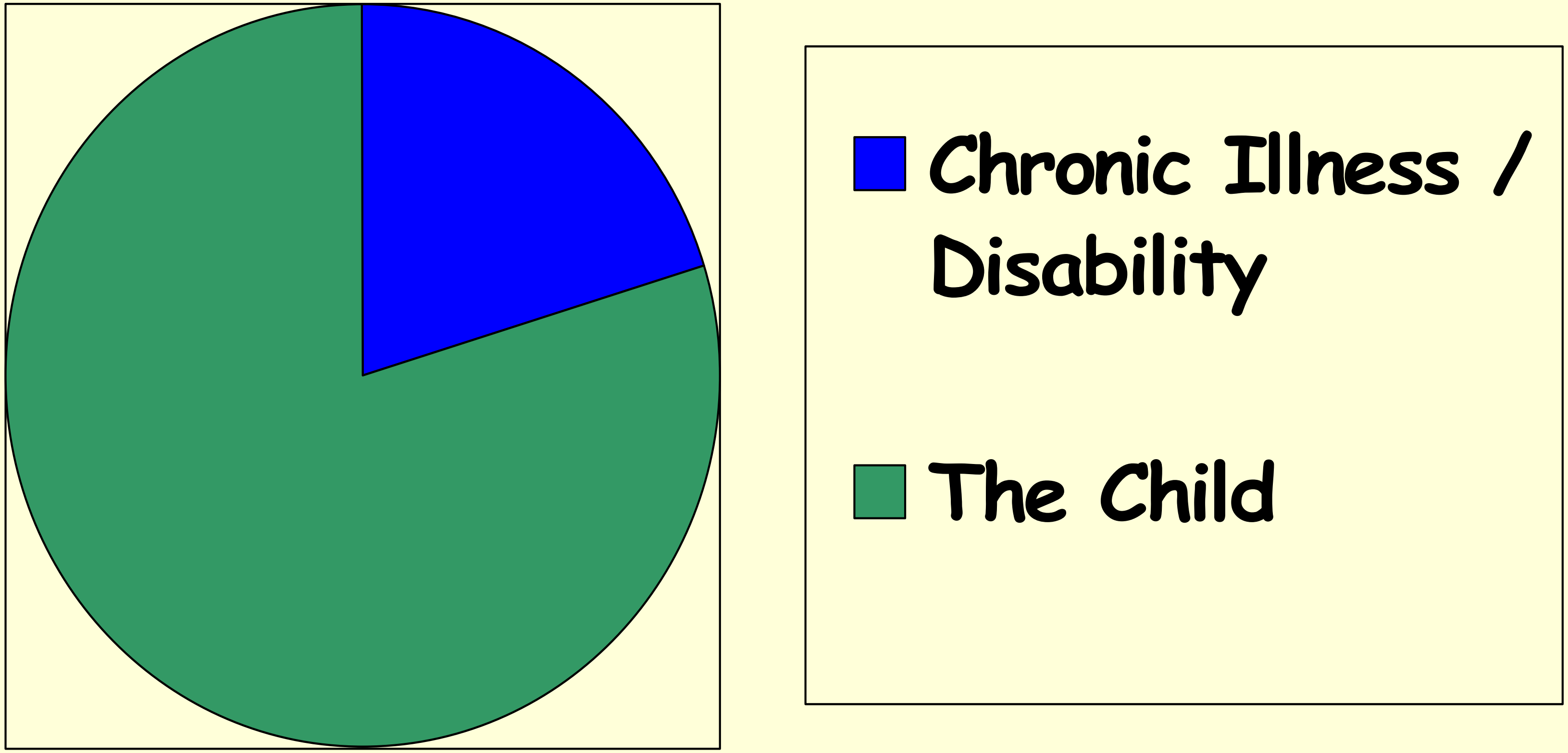
BUT, While we are waiting for a treatment….
We don't have to wait to live our lives!



To live with a rare disorder, means you…

- Take hold of the rare condition and not let it take over your life
- Create a life filled with hope and excitement for living each day to its fullest
- Handle the difficult moments of illness when needed and then be able to live outside the illness when you can

You must see the whole child.



When treating a person with FOP or POH focus on

The TOTAL person

Long term medical management of a patient is inadequate UNLESS a comprehensive approach to the patient is implemented.


Natur


POISON

Comprehensive approach

Whether parenting, doctoring or caring for a person with FOP or POH,

success will demand emphasis on:

1. Individual independence
2. Strong family
3. Quality of life (school, work, play)
4. Happiness of the patient
5. Extended family & community support
6. Timely and appropriate medical care

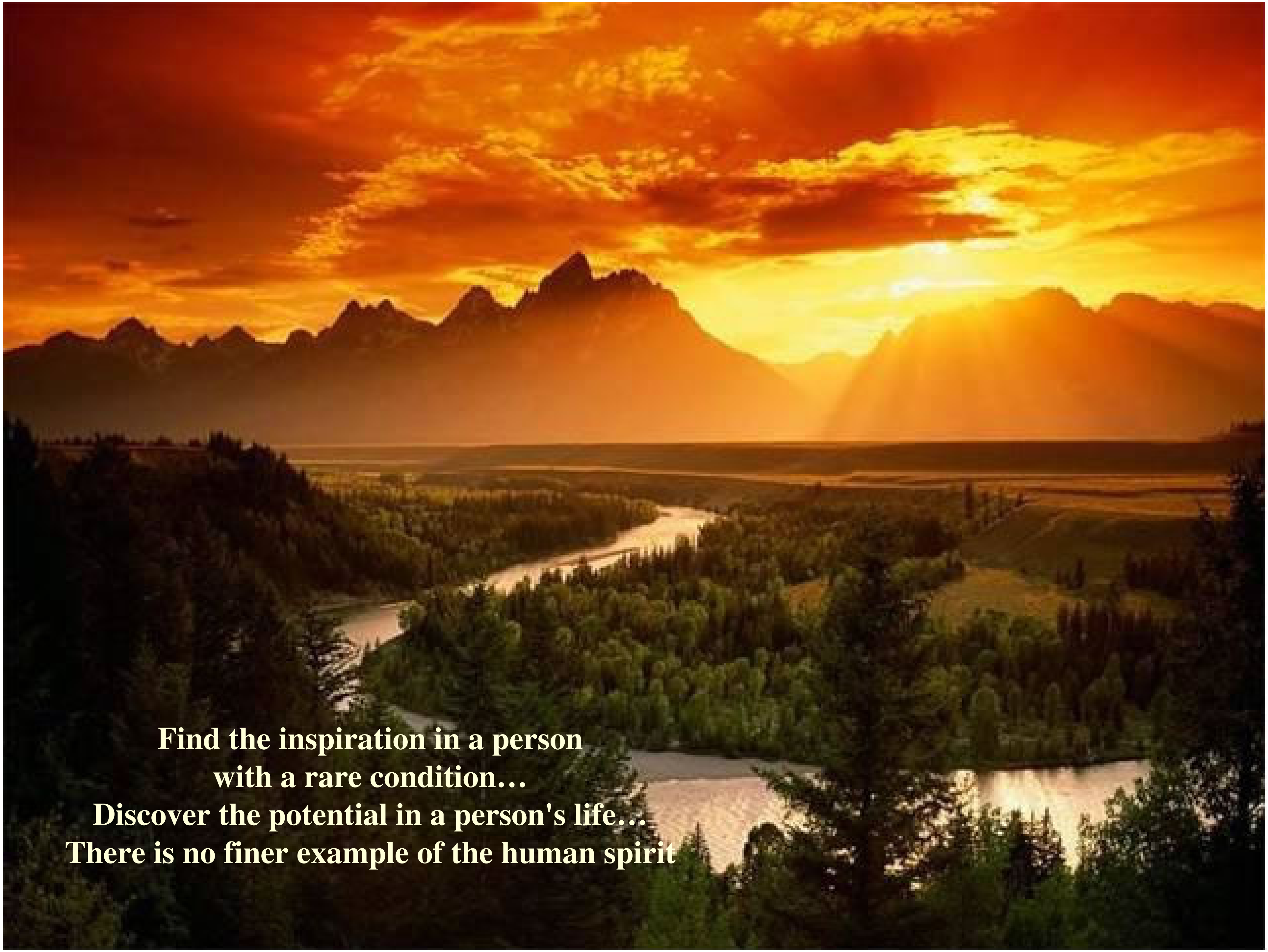
We have choices on how to react to the world that sometimes does not understand

1. Get mad – say something nasty back
2. Take the time to educate the person
3. Learn to have humor and laugh it off
4. Understand the other persons view
5. Don’t go out or explore new places and meet new people

Families and Friendships

Families and Friendships

HOPE in research



Find the inspiration in a person
with a rare condition…
Discover the potential in a person's life…
There is no finer example of the human spirit