

JUAN MAGDARAOG

A LIFE WITH POMPE  
DISEASE

# WHAT IS POMPE DISEASE?

POMPE DISEASE IS A RARE INHERITED  
NEUROMUSCULAR DISORDER THAT CAUSES  
PROGRESSIVE MUSCLE WEAKNESS IN PEOPLE  
OF ALL AGES.

PART ONE:

# A BRIEF HISTORY OF ME



# A BRIEF HISTORY OF ME

- Born Nov 28, 1977 to Victor and Cynthia. Eldest son
- Normal from birth till about the age of 10
- Happy childhood
- Typical Kid. I loved cars and girls
- I'm not 37 years old. Continue to have a happy life

I'm a son, a brother, a loved one, a friend and many other things to many people. I have Pompe Disease but it does not define me.

PART TWO:

# THE CHALLENGE THAT IS POMPE



THE CHALLENGE THAT IS POMPE

# SEVERE DISABILITY

- First symptoms around the Age of 10
- Wheelchair bound by 17
- Nigh time ventilation at 19-20
- Full time ventilation a few years shy of my 30th birthday
- Doctors initially said I would not live past 30
- Dependent on other people for daily living



THE CHALLENGE THAT IS POMPE

# LIMITED OPPORTUNITIES

- Limited physical activities such as sports, recreational activities, etc.
- Limited work opportunities. Could not pursue career choice.
- Limited interaction with other people. Can't bond over sports, travel, etc.





THE CHALLENGE THAT IS POMPE

## EMOTIONAL AND PSYCHOLOGICAL CHALLENGES

- People with Pompe want the same things as “normal” people
- Viewed as different. Object of pity.
- Rejected by peers and opposite sex
- Taunted and teased as a child



THE CHALLENGE THAT IS POMPE

## FINANCIAL AND ECONOMICAL DIFFICULTIES

- Expensive cost of healthcare and supportive devices
- Expensive cost of treatment (ERT)
- Problem is compounded because of lower value jobs or limited employment opportunities
- Lack of support from government/state



PART THREE:

# OVERCOMING LIMITS



“Success is not to be measured by the position someone has reached in life, but the obstacles he has overcome while trying to succeed.”

–BOOKER T. WASHINGTON

# OVERCOMING LIMITS

- When the body is weak, strengthen the mind. Finished school and earned a degree
- Thankful that we live in a time wherein science and technology can give persons with severe disabilities better opportunities
- Gainfully employed and contributing to society
- Lived past what was expected

# OVERCOMING LIMITS

- Lucky to have gotten the chance to get into an Expanded Access Program for ERT. Compassionate use.
- Lucky to have found and worked with great doctors, nurses, therapists and other medical professionals
- Lucky to have met and worked with great people who gave me a chance to be productive.

“The best way to get others to help you is to help yourself. Show them you’re worth helping.”

–ME

PART FOUR:

# MOVING FORWARD





“It is not in the stars to hold our destiny but in ourselves.”

–WILLIAM SHAKESPEARE



MOVING FORWARD

## WHAT I STILL HOPE TO DO FOR MYSELF

- Maintain my health so I can continue pursuing my dreams
- Continue working, learning and being productive
- Continue to build meaningful relationships
- Hopefully a family someday



## MOVING FORWARD

# WHAT I STILL HOPE TO DO FOR OTHERS

- Share my blessings with others
- Continue to advocate for people with rare diseases
- Help change the way people perceive persons with disabilities
- Promote technology as a tool to leading a more productive life

# MY HOPE

- We learn to stop thinking based on economics. Life can't be quantified by money
- Each life is priceless. We can't say what contributions that person can give.
- Each person has a right to live a quality life.
- Government and the private sector work together to help people with rare diseases

# PARTING WORDS

“I have no regrets, because I've done everything I could to the best of my ability.”

–ROBERT REDFORD