

“The Mom”

What’s considered to be a long time at one job? At what point is your dedication respected and honored? What is your reward?

Our organization has existed now for 30 years.

Try to imagine the beginning.

A family is told that their child has a disorder with a strange sounding name that they’ve never heard of – neurofibromatosis.

No one they know has ever heard of it.

There is no email to send out requests for information; no Facebook; no twitter; no internet. Their doctors admit to knowing nothing about the disorder.

They find no organization to help.

Frustrated they realize all they have is the word. No doctor. No support. But they have their voice and determination and they see the need not just for them but for all the others that must surely be out there.

The mom begins to write and call large medical hospitals looking for doctors that have knowledge of the disorder. Still finding no one, she begins to ask if there are doctors that are at least interested in finding out more about the disorder.

The mom finds herself in a new career that she neither trained for nor dreamed of or will ever be paid for.

Eventually she finds a few doctors that are willing to listen and give their time.

She finds other families who have also been looking. They form a local foundation and give families with neurofibromatosis a voice.

They begin in the mom’s basement and move over the years to the basements of others and eventually into the full light of day. The organization grows and the NF community prospers.

Families find each other and find hope.

They nourish clinics, fund research, and learn from each other’s difficulties. They see people they’ve come to know and love succumb to more and more of the devastating effects of the neurofibromatosis.

They become friends and then get each other through the suffering and confusion. They comfort each other when lives are cut too short. They listen to the fears of the newly diagnosed. They reassure, they fund research and they educate.

The mom’s son dies.

The organization and the fight continue to grow by the sheer might and dedication of its volunteers. Using the same strength and determination on which the mom founded it. Some volunteers come and go; some stay on for years and some will stick with it until the organization is put out of business by a cure.

The mom is still here and still in the fight.

While she can no longer save her own son, she continues to carry on the fight and puts the priorities of her life aside because she still has the voice and the determination and she still sees the need. She gives most of her thoughts and a lot of her time to the neurofibromatosis cause so that others can benefit from what has been learned. She continues to make sure that people with neurofibromatosis get the best possible care.

I should have told you a modern story of what we are doing today.

Perhaps a tear jerker about someone who has lost a limb to NF or someone who is dying of a brain tumor and about how we've counseled them to get them the best care or funded research to give them hope.

But when an organization has worked for 30 years and one person has dedicated 30 years of her life to that fight, I think that's the story right there.

So what is the traditional gift after 30 years of work? Is it a 30 year anniversary pin? A paperweight? A nice pension? What is the worth of someone who worked for 30 years at no pay and in the end, no personal benefit to themselves or their family?

The mom, of course, doesn't want accolades or gifts. Moving the fight forever forward is her reward.

Please recognize her efforts and walk beside her in the fight by making a donation or a commitment to help today.

Sincerely,

Diana R Haberkamp
Executive Director
Neurofibromatosis Midwest

<http://nfmidwest.org/donation.html>