

# National Cancer Policy Forum Washington D.C.

February 11-12, 2013

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Cancer Survivor, Patient Advocate

Cancer Research Advocate

Grand Rapids Clinical Oncology Program; Chair, Patient Advisory Committee,  
Executive Operations Board Member

Alliance for Clinical Trials in Oncology; Chair, Patient Advocacy Committee

Midwest Melanoma Partnership; Co-chair, Patient Advocate Committee, Board Member

Gilda's Club of Grand Rapids-Program Mentor

# My Cancer Journey

- The diagnosis
- A clinical trial
- The miracle
- The second cancer diagnosis in 2008
- Making a difference in cancer research

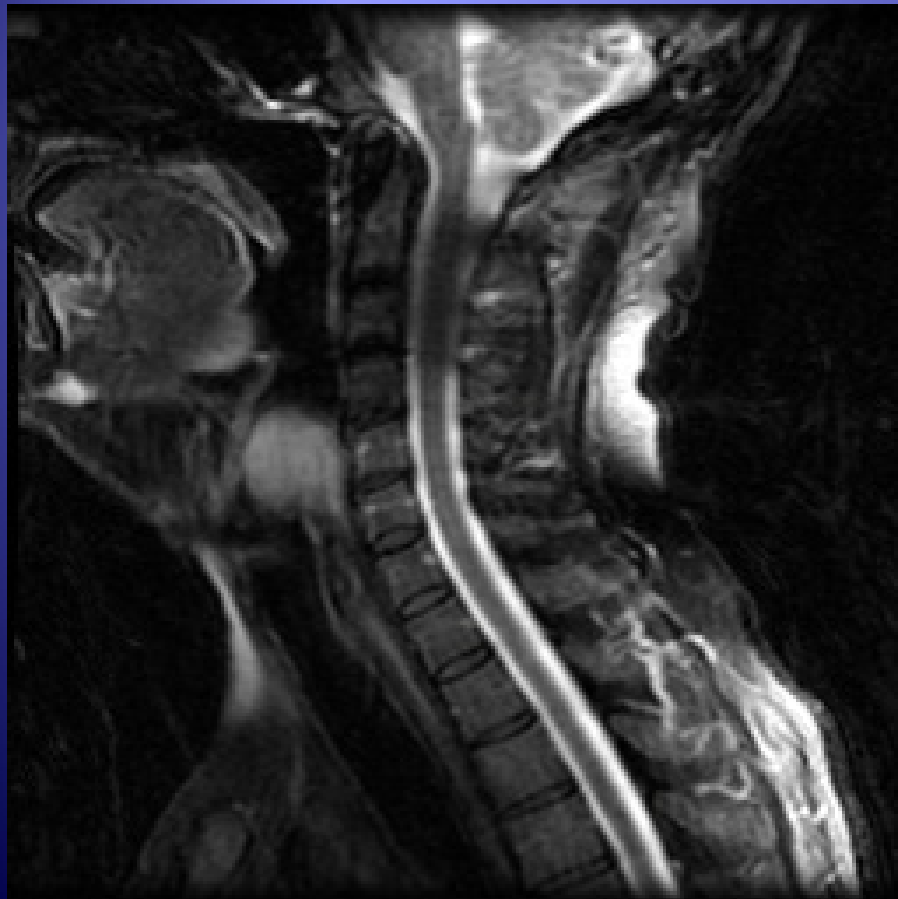
# Dallas Texas March 2007

March 19, 2007 (36<sup>th</sup> Wedding Anniversary)

*Clueless that anything was wrong!!!!*



# My Facebook Pictures in 2007



# The Cancer Journey

**Diagnosis:** *Poorly differentiated invasive squamous cell carcinoma Stage 4 cancer in neck and surrounding lymph cells. (April 2007)*

**The Clinical Trial:** *SCRI HN 08: A Phase II trial of Neoadjuvant Chemotherapy Plus Bevacizumab Followed by Concurrent Chemotherapy with Bevacizumab/Erlotinib/Radiation Therapy in the Treatment of Locally Advanced Squamous Cell Carcinoma of the Head and neck*

**The Miracle:** *“We all had the pleasure of witnessing a miracle, We had new drugs that worked, radiation that worked, a patient with a great attitude, a loving family and a lot of prayers”. Your cancer is gone! (March 2008)*

**The 2nd Cancer Diagnosis:** *Stage 1 Malignant Melanoma (December 2008)*

# April 2007

*“If we continue to do what we have always done, you won’t be with us in six months and we will not have learned anything”*

....my oncologist in 2007

# Making a Difference in Cancer Research

My Plea to Research Nurse:

***“Help me find a way to give  
back for my miracle!”***



# Grand Rapids Clinical Oncology Program (GRCOP) - *A Consortium Approach*

Funded by a National Cancer Institute CCOP Grant since 1983

## Consortium Members

- ① Bronson Battle Creek
- ② Mercy Health Partners
- ③ Munson Medical Center
- ④ Saint Mary's Health Care
- ⑤ Spectrum Health
- ⑥ Spectrum Health Reed City Hospital
- ⑦ Van Andel Research Institute

## Affiliate Member

- ⑧ Mecosta County Medical Center





# Charge to Patient Advocates from GRCOP

*“We want our patients to tell us how  
we can make cancer research in  
West Michigan better!”*

*Connie Szczepanek RN, BSN  
GRCOP Director*

# Patient Advisory Board for Clinical Research

Established May 2008



**Grand Rapids Clinical Oncology Program**

Committed to Community, Cancer Research, and Education

# Experiencing a Miracle

My challenge to you is:

*“How do we make more miracles?”*

...Pat Gavin 2013

**Why was I a miracle when other patients just like me were not?**

*How do we make “personalized medicine” a reality?*

*Patient involvement in the trial development process is key*



# We are Committed to Personalized Medicine!



# Patient Advocates:

- Provide the patients' perspective to researchers and clinicians throughout the development and implementation of clinical trials
- Facilitate the development and implementation of patient centered trials
- Develop strategies that accelerate study development, activation, accrual, participation and reporting
- Ensure clinical trials are selected that affect clinical outcomes of people with cancer

# The voice of the patient

*We ask probing questions not to be difficult/adversarial ... but only to satisfy our responsibilities as a representative of the patients who face the disease*



# An Uphill Battle



# Logistical Challenges

- We can't have clinical trials that are only available at the large cancer centers. These trials have to be available in the community.
- We can't continue to just focus on large, easy to accrue trials. We have to ask the hard questions in the community.
- We have to be able to engage the community oncologist and their patients.

**We can't hide behind the  
current obstacles**



# The National Clinical Trial Network

**GOAL:** Conducting research that can bring miracles to all patients

**Challenge:** It is likely that achieving personalized medicine will be required to successfully treat individual patients

*It is not possible to conduct clinical trials to achieve personalized medicine without engaging the broadest possible patient community*

# The Advocate's Role in Communication

- Engaging the broader advocacy community
- Educating the public on the availability of clinical trials as a treatment option
- Developing patient-centered materials to help treating physicians discuss trials with patients
- Publishing and disseminating clinical trial results in plain language



# Outreach to Patients

[www.grcop.org](http://www.grcop.org)

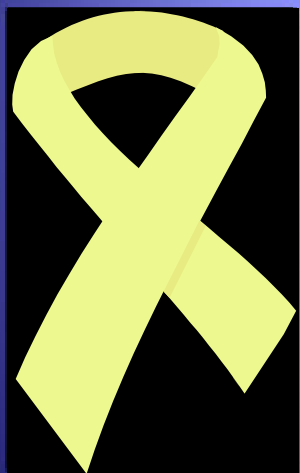
[www.lymphomation.org](http://www.lymphomation.org)

[www.cisncancer.org](http://www.cisncancer.org)

# Cancer Clinical Trials...

WE HAVE

Real Answers, Real Options, Real Miracles  
Right here in our community!



*...Hope for the Future*

*Grand Rapids Clinical Oncology Program (CCOP)*



