

Diagnosis Brain Tumor: You Are Not Alone IV

Newly Diagnosed – Now What?

October 2011

Diane Bier



Gray Matter Matters

Agenda

- ⚪ Why Me???
- ⚪ Resources
- ⚪ What to Do/What Can I Do
- ⚪ Diagnosis
- ⚪ Doctor Appointments
- ⚪ Standard of Care - Treatment
- ⚪ Side Effects
- ⚪ Take Time – Quality of Life
- ⚪ Coping
- ⚪ Ask for What You Need
- ⚪ Celebrate Life
- ⚪ Thrive



Why Me?

**"I don't have time for
brain tumors!
I have too much to do."**

What fun is life you cannot laugh?



David Bier



Resources

| Organization | Web Site |
|--|---|
| NJ Brain Tumor Support Group | www.njbt.org |
| Musella Foundation (Virtual Trials) | www.virtualtrials.com |
| Stupid Cancer – I'm too young for this | http://www.imtooyoungforthis.org/stupidcancershow/index.shtml |
| Social Security Compassionate Allowance | http://www.socialsecurity.gov/compassionateallowances/conditions.htm |
| Clinical Trials.gov | http://clinicaltrials.gov/ |
| Seeking Peace - Brain Tumor Hospice Care | http://brainhospice.com/ |
| Tug McGraw Foundation | www.tugmcgraw.com |
| American Brain Tumor Association | www.abta.org |
| Pediatric Brain Tumor Foundation | http://www.pbtfus.org/ |
| Childhood Brain Tumor Foundation | http://www.childhoodbraintumor.org/ |
| Duke University Center for Living | www.cfl.duke.edu |
| NIH – Brain Tumor | http://www.cancer.gov/cancertopics/types/brain |
| Caring Bridge | www.caringbridge.org |
| Lots of Helping Hands | www.lotsahelpinghands.com |
| Angel Food Ministries | http://www.angelfoodministries.com |
| CURE - Cancer Updates, Research and Ed | Free subcription. Call 1-800-210-CURE (2873) |
| Randy Pausch video | http://video.google.com/videoplay?docid=8577255250907450469 |



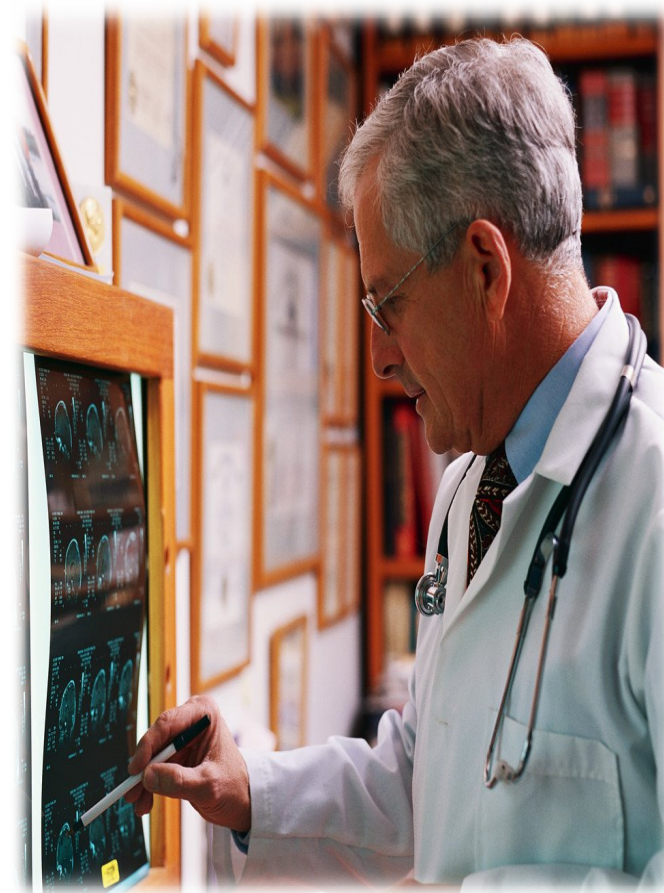
What to do/What can I do?

- ⚪ Stay positive
- ⚪ **Be your own Advocate**
- ⚪ Build a medical team to help you
 - Find a good surgeon and neuro-oncologist
 - Add neuro-psychologist and others as needed
- ⚪ Educate/research your tumor type
- ⚪ Build a support team
 - Family/friends
 - Religion
 - Join a Support Group



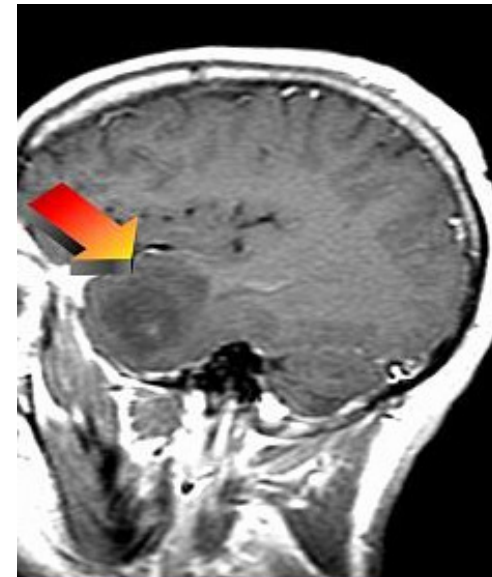
Diagnosis

- ⚪ Standard treatment before experimental
- ⚪ 2nd opinions at NIH or Major BT Center
 - Don't ever look back and think you made the wrong decision no matter what happens
- ⚪ Pathology
 - Treat for the highest tumor grade
- ⚪ Keep a copy of all medical records
 - Surgeon's reports
 - Radiation reports, type & amount of radiation
 - Pathology report
 - All MRIs and reports
 - Keep all scheduled appointments
 - Scan all records into the PC
 - Backup MRI CD's



Doctor Appointments

- ⚪ Plan on waiting, bring a book
- ⚪ Bring all reports, MRIs, etc
- ⚪ Keep a journal
- ⚪ Take someone with you
- ⚪ Bring a tape recorder
- ⚪ Write questions before you see the doctor
- ⚪ Make sure your questions are answered to YOUR satisfaction
- ⚪ Ask for scripts to be filled



Medication Sheet - Sample

My Medication Notes

| Medication Name | Dosage | Prescribed By | Purpose | Usual Side Effects | Dangerous Side Effects | Pharmacy & Ph# |
|-----------------|--------|---------------|---------|--------------------|------------------------|----------------|
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Standard of Care - Treatment

⚪ What is standard treatment – do what works for most patients first

- Surgery/biopsy
- Vaccines
- Gliadel
- Pathology Report
- Radiation
- Chemotherapy
- Avastin



⚪ Clinical Trials – after standard of care no longer works

- Vaccines
- Novocure



Side Effects

☎ Surgery

☎ Radiation

☎ Chemo

☎ Memory Issues

☎ Seizures



Take Time – Quality of Life



Take time to relax

- Have a cup of tea
- Meditate
- Read a book
- Take a walk



Get enough sleep



Develop a routine



Find Alternates/Substitutes if needed



Nutrition

- Don't skip meals
- Eat nutritionally dense foods



Exercise

- Relieves stress
- Helps you sleep



Coping

- ☯ New “normal”
 - The first year
 - Surgery, radiation, chemotherapy
 - “Normal” changes
- ☯ Take it a day at a time
 - Break it down to small parts of the day, e.g., breakfast, lunch, the afternoon, etc.
- ☯ Keep a list of who does what, maintain a calendar
- ☯ Talking to children
- ☯ Use email
- ☯ Find others who are “long-term” survivors
- ☯ Find a “live” Support Group in addition to online groups



Ask For What You Need

☎ Counseling

☎ Off load

- Cooking
- Cleaning
- Laundry
- Grocery

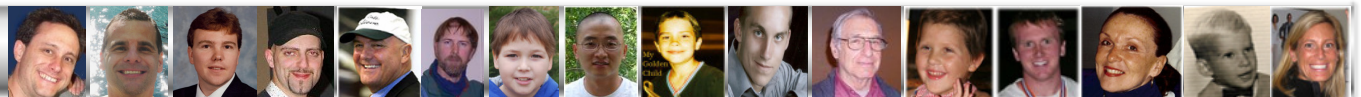
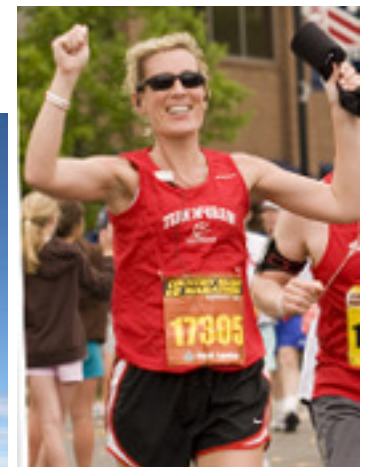
☎ Childcare

- Drive/pickup to school/activities
- Babysitting
- Homework



CELEBRATE LIFE

- ☯ Stay positive
- ☯ Be your own advocate
- ☯ Be the exception
- ☯ Have a sense of humor
- ☯ Enjoy the good days/moments
- ☯ Have an anniversary party
- ☯ Do the things you love



Thrive

**"Whether you have 50 years, 5 years,
5 days, 5 hours, or 5 minutes,
you need to live your best life."**

"Attitude determines Altitude in Life."



**Jimmy "SuperFang" Fang
1974-2007**

