

Matched Sibling Donor Transplant

The Fiaschetti FAmily Experience



December 2, 2009 Day 0

Fanconi Anemia Diagnosis

Peter was born in August 1999 with hypoplastic thumbs.



Diagnosed February 28, 2000 at 6 months old with Fanconi anemia.

Within 2 months, informed big brother Joey was a perfect 6/6 match.



The only known cure for
bone marrow failure
is a
Bone Marrow Transplant.

Early Decisions

- Learn as much as possible about Fanconi anemia (FA)
 - FARF: handbooks, newsletters, etc.
 - Camp Sunshine
 - FAmily online journeys (blogs, caringbridge, etc.)
 - Regional FA meetings
 - E-group
- Move near a recognized transplant center
- Seek treatment at a recognized transplant center (referrals, insurance approval for out of network provider, etc.)
- Adopt healthy habits
- Raise \$\$\$\$ for FARF to fund a cure
- Appreciate every day—live life

Insurance

- Request a case manager from your insurance.
- As transplant nears, request a transplant case manager.
- Be willing to make hard decisions to maintain insurance.

Doctor/Patient Relationship

- Establish a relationship with transplant hospital & hematologist early on
 - Routine screenings and appointments develop into a trusting patient- doctor relationship



- Peter's first visit with Dr. Alfred Gillio , Hackensack University Medical Center's Children's Hospital, in Sept 2002 at age 3
- By transplant Nov 2009 - Peter was very comfortable with and trusted Dr. Gillio & staff , age 10

Be Honest with Your Child

- Educate your child about FA (age appropriate level)
- 6-12 months out started discussing the transplant process with age appropriate material in small intimate loving sessions
 - Sources:
 - Pediatric hematologist “My Bone Marrow Transplant”
 - Be The Match “Me and My Marrow”
- Talk about it all - the good, bad and the ugly
- Be Positive! * This is a Life Saving Experience*

Ready Entire Family

Divide responsibilities with partner/others

- Fielding insurance issues
- Medication/Medical appointments
- Communication with School – both for patient and siblings
- Household
 - Bill paying
 - Care of siblings
 - Extra help needed to grocery shop, cook meals, laundry, clean house, etc?

Important Information Sheet

- 1 page (2 sided) document containing the following:
 - Child's name, date of birth, address
 - Medical History
 - Congenital anomalies
 - Surgeries
 - Medications
 - Hematology status & transfusion history
 - Points of Contact (include name, address, phone, fax, ID #)
 - Parent
 - Primary Care Manager – Pediatrician
 - Transplant Hematologist
 - Local Hematologist
 - Insurance and assigned Transplant Care Manager

*****Make Multiple Copies and Carry it at all Times*****

Education

- School provided a tutor while in isolation at home before and after transplant
- Hospital Education Coordinator
 - Establish video link with patient's classroom
 - Follow same curriculum
 - Provide written requirement for special education accommodations after transplant (Summer tutoring, IEP, 504, etc.)

Communication

- Within immediate family
- Extended family & friends (caringbridge site)
- School
 - Patient's teacher
 - Alert sibling's teachers to situation at home
- Wireless Internet / Computer access

Transplant Facility

- Tour with child ahead of time
- Patient privileges
- Parent privileges
- Restrictions
 - Discuss special meds or foods with dietician & doctor
- Visitor policy
- Patient room - Making it kid friendly
 - Bed sheets from home
 - Holiday decorations
 - Books, music, special video games
 - Family photos/ posters
 - Soft pajamas and hats

Extended Stay

- Discharged from inpatient care but need to stay locally
 - Find out before leaving for transplant what expenses your insurance will cover for patient and adult companion
 - Your social worker can assist with local lodging (Ronald McDonald house, etc.) and any other items you might need during stay

Matched Sibling Donor transplants can have complications.

BK Virus

Acute Skin GVHD

Abnormal Cell Growth – tongue & toes

FAMILY Suggestions

- Travel lint brush (sticky wand kind) – roll over child's head to remove loose hairs from chemo
- Wrapped prizes/rewards for mouth care
- Daily Activity Chart
- Bring something soothing for adult while child is sleeping during daytime: book, Bible, knitting, iPod with favorite soothing music, laptop, electronic games

Carpe Diem - Have Fun Whenever Possible

Friday Food Parties

Ice Cream Sundae Party



Warm Chocolate Chip Cookie Party



Rice Krispie Treat Party



Nerf Gun Target Practice



Ninja Power Karate Class



Limbo Party after BMA



Peter's BMT Diary

- Day -7 Admit & Central Line placement
- Day -6 through -2 Chemo drugs:
Fludarabine, ATG, Cytosin
- Day 0 Transplant Day





- Day +12 Engraftment WBC 1.2
- Day +19 BK Virus, hemorrhagic cystitis Grade III, severe
- Day +30 Discharge to outpatient care



- Day +44 Readmitted with fever
- Day +47 Acute GVHD, Clinical Stage 3 of the Skin, Grade II (Moderate)
- Day +54 Discharge to outpatient care



- Day +85 Welcome HOME!





- Day +100 Celebration with restaurant food all day long
- Day +103 Ingrown toe nails
- Day +140 Central Line removed
- Day +153 Tongue lesion forms
- Day +182 CBC- Everything in Normal Range!



- Day +204 Camp Sunshine



- Day +210 Discontinue cyclosporine
- Day +275 Return to school
- Day +317 Surgery on toe nails



- Day +365 1 year post BMT, reimmunization begins



Transplant forever changes
everyone in your
family.



7 Mile Bridge
Florida Keys
14 months post BMT