

DOWN SYNDROME FAMILY SUPPORT AND ADVOCACY GROUP



Grief Can Be a Gift

By Sally Nantais, The News-Herald, August 1,

With the dog days of summer upon us, I was sitting at this silly computer trying to find the direction for a column. My mind wandered far from summer to a personal experience.

It's a unique experience that only a parent of a child with a disability can understand: the grief that one experiences with a diagnosis of a disability.

These thoughts were brought on by the images of Nancy Reagan having to be coaxed from her husband's coffin, so weary and grief-stricken. It's a vision some of us won't quickly forget.

It intensified with a column I read for the Grosse Pointe News by close friends Mary Beth Langan and Ted Coutilish on "D-Day," which had nothing to do with World War II. "D-Day" for them was "Diagnosis Day."

Having a child with a disability is not something one ordinarily chooses. The beginning, the diagnosis stage, is one of the most difficult.

We all have dreams for our children that may be shattered with a diagnosis of a disability, be it physical or developmental.

With the loss of those dreams comes grief and all the emotions that go with it: denial, fear, guilt, blame, anger, sorrow and acceptance. Grief doesn't exclude things we can't see or touch.

Grief over our shattered dreams can be as intense as that for the death of a loved one.

Denial came first. "They can't be right, look at what he can do, at how bright he is?" Why do they measure our children on what they can't do and not by what they are capable of doing?

Fear of the unknown is always present. As a parent, you want to know as much as possible and have all the answers. Unfortunately, you quickly discover there are no answers for the important questions. Will my child have friends? Will my child be happy?

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Are you on our Birthday list?



The DSFSAG are happy to announce that we have started a new tradition of sending birthday greetings to all who have Down syndrome on our mailing list. Unfortunately we don't have everyone's birthday date yet, if you would like to have your child or family member receive one of our birthday greetings please contact Tonya Albertson at 219-778-9049 or at bteatrp421@verizon.net. We are excited to get these birthday greetings sent out every month so we can let everyone in our Down syndrome community know that we are thinking of them, how important they are to us and that we are celebrating their special day with them. Thank you.

Grief continued

Will my child be able to live independently when he's older? What will happen to my child when I'm no longer able to care for him?

Guilt and blame quickly followed, which for me was an easy trap to fall into. After all, my son's disability, Fragile X syndrome, is genetic.

Prior to his diagnosis (he was diagnosed when he was 4) I had no idea that I had a 50/50 chance of passing a developmental disability to my child.

Anger became apparent when I questioned why this happened to me. I wondered why I had to be the one to pass it on and not one of my sisters? It didn't seem fair, but is life ever fair?

At times, my anger has been misdirected. My son has a condition that he was born with and he will die with.

At least that's how one insurance company explained a denial of service to a parent of a child with Fragile X syndrome. At this time, it's not curable and it's not terminal.

There's no Make A Wish or Rainbow Connection for my child or other children like him. Sometimes it seems as though no one cares about the quality of his life, or others like him.

Sorrow was never as intense as it was in the beginning. It's difficult to explain the depth of your sorrow: It was, and at times still is, immeasurable.

Surprisingly, sorrow didn't occur immediately, but happened a little later when hearing the words "mentally retarded" used to describe my son's disability.

Grief may never completely end, but its intensity can subside. From time to time it will resurface and I've learned to welcome it, as it gives me the opportunity to be reborn.

In the movie, "Harry Potter and the Chamber of Secrets" there is a special bird called a phoenix. The phoenix has some unusual characteristics.

When he reaches the end of his life, he bursts into flames and is reborn from his ashes. His tears can heal the wounded and he has the ability to carry incredible loads.

There are times when I feel like the phoenix. I need to burn up so I can start over. From the ash comes additional strength and courage to go on and never give up.

My tears may not heal the wounded, but they do heal me. Lastly, it feels as though the weight on my shoulders is almost unbearable, but I've managed to carry it.

With the passage of time my grief has become a gift. Another door has opened in which my life has become more meaningful. One day, my husband asked me to imagine our lives without our son.

I could describe it with a single word: "shallow." I've found you can live a "shallow" life just as easily as you can drown in shallow water. It's only a matter of choice.

Strangely, many years ago "perfect" was something I strived for. Now, I strive for less than perfect.

All because of a child who may never be "perfect," who may never be "normal," but who will simply love me with all his heart, no matter what.

A lesson learned through the process of grief.

Mini Grants

Starting January 1, 2008, members of the Down Syndrome Family Support and Advocacy Group can apply for a \$200 mini grant to help with educational and medical costs for the member with Down syndrome. Members are eligible to submit only **one** application per year, but can **combine receipts** to total a maximum of \$200.

Below are some examples of mini grant eligible expenses. It is impossible to list everything, so if you have a question about an expense not listed, please ask.

- Costs for DS conferences/ DS education resources
- Medical bills
- Medicines
- Eye glasses
- Orthotics
- Hospitalizations
- Dental care
- Hearing aides
- Therapy
- Surgeries

Remember that you can submit only one application per year for a maximum reimbursement of \$200.

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Mom's Night Out

Hey Moms - need a night out to talk, laugh and have fun? If so, come and join other moms who share that wonderful common interest of having a child with Down syndrome. The group meets once a month at local restaurants. All we ask is that you PLEASE RSVP no later one day prior to the scheduled meeting date at:

New for 2008....

DSFSAG Mom's who RSVP will receive \$5 to be used towards their food purchase. You must be a member of the DSFSAG to receive the \$5.

2008 Meeting Dates:

Restaurant locations and if applicable, date changes or cancellations are posted monthly on the [Michiana Down Syndrome Listserv](#).

March -Tues 03/11/08 Hacienda - Portage

April -Thurs 04/17/08 Between the Buns - Lincolnway (Twin Branch) Mishawaka



Good food even better company.

May - Tues 05/13/08 Red Lobster - Main Street, Mishawaka

June -Mon 06/16/08 Fazoli's - McKinley, Mishawaka

July - Thurs 07/10/08 BW3s - Downtown South Bend

August - Mon 08/18/08 Culver's - Main St, Mishawaka

September - Thurs 09/11/08 Applebee's - Bittersweet & Lincolnway, Mishawaka

October - Tues 10/14/08 Logan's - Erskine Plaza, South Bend

November -Mon 11/10/08 Panera Bread - Erskine Plaza, South Bend

December - Thurs 12/11/08 Papa Vino's - Main Street, Mishawaka

Family Support Nights

Great way to meet other families, share information, and get resources.

Logan Center
2505 E. Jefferson Blvd.
South Bend, IN
6:00 p.m.
Free child care provided

MEETING DATES for 2008

- March 7th Explaining the Medicaid Waiver - One hour presentation by Cheryl Schade from Logan
- April 25 Talent Show! All kids and adults' w/DS and their siblings are invited to take part in the talent show. Read a



story or recite a poem, sing, show off your karate moves, play the piano, guitar, dance, jump rope, bring your art work for display, etc. Babies can even show off the sign language they are learning.

- May 30 New Family Welcome Party
To welcome families who have joined the group since our last party to welcome new families in 2006..everyone invited
- June 20 Guardianship Anne Kallenberg, Protective Services at Logan Center, will talk about guardianship

DSFSAG
51201 Old Cottage Dr
Granger, IN 46530

Phone:
574-243-3808

Web:
www.michianadownsyndrome.org

Taking steps for a
brighter tomorrow

Mini Gats continued →

Example of eligible applications:

Submit application in June for the following: \$50 eye exam in January, \$100 dental expenses in February, and \$50 education materials purchased in June = \$200

Examples of non-eligible applications:

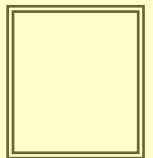
Submit an application in February for \$75 for glasses. **The \$75 is eligible and was paid.** Then in June, submit a second application for \$125 for dental expenses. **The second application for \$125 is ineligible for reimbursement and will not be paid.** Only one application per year is permitted.

There is limited number of grants. All mini grant requests will be subject to approval by the Board. Grants will be awarded on a reimbursement basis only. If a family has more than one member with Down syndrome, they may apply for one grant for each person with Down syndrome. In the event a grant is not awarded, the request does not roll over to the next year. Receipts submitted must be for the current calendar year.

To request consideration for a mini grant, send application to: (application can be found online or contact us)

DSFSAG Mini Grant
51201 Old Cottage Dr.
Granger, IN 46530

DSFSAG
51201 Old Cottage Dr
Granger, IN 46530



Customer Name
Street Address
City, ST ZIP Code