

Introducing... JustOneMoreDay.org

On August 3, 2005, my daughter Alicia was diagnosed with a *diffuse intrinsic pontine glioma*. On that day her doctors told us she had, at best, 12 to 18 months to live. I remember the shock and thinking they HAD to be wrong. I began my frantic search for information. I spent countless hours on the internet searching for treatment options. With only 12 to 18 months to spend with my little girl, every moment counted. I do not regret the time I spent searching for something--anything-- to help her. If there was one website that I could turn to and find all the information I needed, think of the time I would

have saved! After my sweet little girl passed away, I knew this was something I needed to do.

[Just One More Day.org](http://JustOneMoreDay.org) was created to provide families with information about *diffuse intrinsic pontine gliomas*. Our hope is to make this journey a little easier and to save these families precious time.

We are updating and adding information frequently so please visit us often. If you have any information you think we should add to our website please send your ideas.

JustOneMoreDay@cfl.rr.com



*Alicia Marie
Martin*

**September 11, 1998 ~
December 23, 2006**

**Alicia's Journey
with a D.I.P.G.
[YouTube Video](#)**

New Online Support Group for D.I.P.G. Families



Erika Hauschildt, mother of 7 year old Ella who has a *diffuse intrinsic pontine glioma*, recently established an online support group exclusively dedicated to D.I.P.G.'s. Many families have already joined this active

group which gives parents an opportunity to share helpful information and provided support for others on the same journey. Click on the link to join this group.

[D.I.P.G. Parents](#)

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Just one more day...
to hold your hand.
Just one more day...
to find the best doctor.
Just one more day...
to laugh with you.
Just one more day...
to find the right treatment.
Just one more day...
to kiss and hug you.
Just one more day...
to find a **cure!**
Just one more day...
to say **I LOVE YOU....**



*Together
we can
make a
difference...
find a
cure!*

Families Making a Difference

Diffuse intrinsic pontine gliomas are the worst kind of tumors--in the worst location. Families can no longer sit back and wait for something to happen; we must join together in the fight against this tumor. There are many benefits to joining Just One More Day; you will receive our newsletter, you will automatically be subscribed to receive our e-mail updates, we will promote members events and fundraisers designed to raise money for DIPG research and/or awareness, and we will provide a page on JustOneMoreDay.org to honor your child.

To join Just One More Day...

Parents, guardians and close relatives of children with pontine gliomas are invited to join Just One More Day. The only requirement is that you must have a desire to make a difference--to end the suffering by finding a cure.

The process is rather simple. Fill out the consent form found in the *About Us* section. When you join, you will have the opportunity to establish a page on this website in honor of, or in memory of, your child. This page may include pictures of

your child, your child's story, and ways you plan to support Just One More Day. Events will be listed on the home page.

Your part is simply to honor your child by raising awareness and/or by raising funds to help Just One More Day support research. You may choose to have a fundraiser once a year or as often as once a month. The goal is to raise money and awareness throughout the entire year. The funds raised will be combined to provide grants for research. Together we can make a difference. Together we can find a cure!

Alicia's Angels

is very rewarding because you can make a difference.

Angel Fundraising Ideas

1. Collecting Pennies
 2. Selling lemonade
 3. Selling cookies
 4. Washing cars
 5. Walking dogs
 6. Having a garage sale
- Any donation is greatly appreciated.

If your child--or even you--would like to become one of Alicia's Angels, please submit an [email](#) containing the following information.

1. Parent's name, address, phone number and email address
 2. Child's first name and fundraising idea(s)
 3. Your child's picture or picture taken at fundraising event
- Please send funds to the following address.

Just One More Day
1853 Surrey Court
Viera, Florida 32955

Each month's most successful angel will be recognized on the 15th of the following month. Together you can make a difference !



Ashley, Alicia's sister and one of Alicia's Angels

Alicia's family truly believes Alicia was always an angel--even before she earned her wings. Every child has angel characteristics and abilities; we often overlook these wonderful traits. *Alicia's Angels* are children who are helping other children by performing selfless acts that will eventually change our future. The funds raised by these angels will help support brain tumor research... and someday a cure.

It's easy to be an angel! It does not require a lot of time or hard work, and it

Angels are all around us.

Parent Pointers

Parent Pointers is a new addition to *JustOneMoreDay.org*. Here are a few examples of *Top Tips* which can be found on the website under *Parent Pointers*.



Make sure you are comparing apples with apples. At one time all brainstem gliomas were lumped together, however, they are no longer considered one entity. If you are

comparing other situations to your own, make sure that they are truly similar. Other brainstem gliomas--and high grade gliomas--elsewhere in the brain act differently from D.I.P.G.'s.



Connect with other parents through [online support groups](#).

We recommend [D.I.P.G. Parents](#).



Start a file to handle finances. Become familiar with your medical benefits. Keep the EOB's (explanation of benefits) sent to you and compare it to the bills you receive. Billing mistakes can happen, so review the bills carefully.

To find more *Top Tips*, go to [JustOneMoreDay.org](#)



Alicia

Understanding Pontine Gliomas

This section of *JustOneMoreDay.org* has been enhanced recently. It has been written in layman's terms to provide a better understanding of this particular tumor.

- What is a glioma?
- Where is the pons?

- What does the pons do?
- What are the typical symptoms?
- What does it look like?
- What else should I know about D.I.P.G.s?

What does it look like? contains pictures of MRI scans: a normal brain; Alicia's brain at diagnosis, after radiation and during tumor progression. *What else should I know about D.I.P.G.s?* contains answers to frequently asked questions.

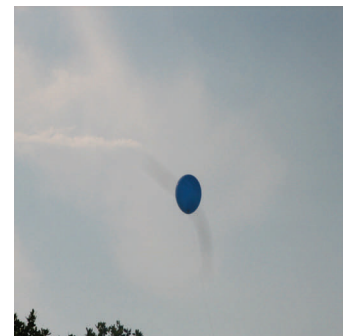
"Little progress has been made in prolonging the lives of children with diffuse intrinsic pontine gliomas in the past 30 years."

Treating Pontine Gliomas

This new section of *Just One More Day.org* is a work in progress. Treating a pontine glioma is a very complex process. Due to the severity of D.I.P.G.s and limited treatment options, this section is attempt to address all possibilities.

- Surgery
- Radiation
- Radiosensitizers
- Chemotherapy
- Steroids
- Imaging
- Nutrition & Supplements
- Complimentary & Alternative Medicine
- Palliative care & Hospice
- Clinical Trials

Join our [mailing list](#) to receive website update notifications.





JustOneMoreDay.org

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for Love, Hope & a Cure....
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Visit us on the web!

JustOneMoreDay.org

Just One More Day... for Love, Hope & a Cure....

is committed to increasing awareness
about diffuse intrinsic pontine gliomas,
funding research, and providing information
for the families of children
who are living with this type of cancer.

Alicia's Story

Alicia Martin was an out-going, energetic, sweet six year old girl who loved swimming, cheerleading, reading and school. Alicia was enjoying her last week of summer (2005) and playing with her sister Ashley, when she started having double vision. Her mother was concerned because Alicia had bumped her head while playing in the pool the day before. She was taken to the local emergency room, and the doctors said her head was fine where she bumped it. However, they found something more troubling. Alicia was rushed to Florida

Hospital in Orlando where there they performed an MRI of her brain. They noticed a tumor in her brainstem. She was diagnosed with a *diffuse intrinsic pontine glioma*. Alicia is one of less than 250 children in the United States diagnosed with this condition each year.

Alicia battled this tumor for almost eighteen months. She bravely fought and rarely complained. Sadly Alicia passed away in her mother's arms on Saturday, December 23, 2006 at 6:15 p.m. *Just One More Day* for

Love, Hope & a Cure will help preserve the memory of a true angel

~ Alicia Marie Martin. She touched many lives during her short eight years on earth. She will be forever missed, yet *never* forgotten. To learn more about Alicia and her journey please visit her [website](http://www.justonemoreday.org).



***Alicia three days
before diagnosis***