

“My Favorite Time of the Year is here!”

By: Laura S. Nata

May has always been my favorite month of the year that I find most meaningful! This is when you hear about whose child is graduating from high school.



Something else happens, your child with disabilities ages into the adult world, whether the person is prepared or not.

For typical youngsters, plans are made before exiting high school. They have employment lined up, chosen a college to attend or sometimes move to another state to pursue a career. But for some of our children who have a disability, the planning is not that easy. To make this happen, it takes years of planning throughout their years in school, and 100% support from the household, extended family, caregivers, educators and other individuals.

This is my story. At the age of five, my child acquired West Nile virus which resulted in encephalitis that effected his entire nervous system. In some cases, swelling of the brain can lead to permanent brain damage and lasting complications like learning disabilities, memory loss, speech, behavior and balance problems, all of which he experienced. It was said he would never talk, walk, learn or have an ordinary life. For many years, due to his impairments, he required physical, occupational, and speech therapy.

During his years of therapies and visits to specialty doctors, with much practice he eventually learned to communicate his concerns regarding his healthcare. This is another learning opportunity for the young child to learn, since eventually there will come the day he/she will have to take over their medical responsibilities. We kept good health records on all his doctor visits. For some families this is a huge task to keep all documentations in order. This is why FHF is giving you the opportunity to learn how to create one.

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This month we are having a workshop on this very topic: **Managing Your Child's Medical Information**, Wednesday, May 13, 2015, from 10 - 12 pm at Metairie Road Library, 2350 Metairie Rd., Metairie, LA 70001. Register with us at this link: <http://fhfjefferson.org/Events/eventscalendar2.asp> or simply call our office at 504-888-9111. I encourage you to join us in creating a system to manage doctors' recommendations, appointments, medications, and build a historical record for your son/daughter. Remember your child will eventually transition from pediatrics care to adult health care.

Moving forward, I looked for recreational opportunities since I knew he would have difficulties with sports. He learned how to swim thru Jo Jo's Hope, did hippo therapy from Greater New Orleans Therapeutic Riding Center (horseback riding) and joined a karate class. We had to be mindful of his physical fitness.

Every day became therapeutic and learning moments. I applied fun to my teaching so to maintain his focus. His father would bake cakes on Fridays just for him until he learned how. He had to read the instructions, measure ingredients and then apply those instructions to what he was doing. By being introduced to comics, Pokémon and car magazines, he learned early on to love and enjoy reading. He joined Pokémon trading cards events and competed against other players. This is where he sharpened his memory, reading, and math skills.

Your child's school years are a treasure so don't miss an opportunity to meet and maintain a working relationship with the professionals that are teaching or providing services to them. Where my son fell short, I provided the help needed for him to reach all his goals year to year.

Because of slowness of movement, I had to teach him to always organize and prepare himself for school the night before so that we did not have to rush in the mornings. Our daily routine during the week looked like this; once home from school he was persuaded to go out and play or just to socialize. Six o'clock was the hour to come in and do homework without any interruptions. Each day the DO NOT DISTRUB sign was hung on the door, we played classical music to drown out the outside noise, phone/TV was turned off and used lavender air freshener to create a soothing and calm environment.

We prepared him with skills for employment by exposing him to a wide range of work with his dad as a General Contractor and duties at home. By the age of sixteen he actually went out and applied for a weekend job at our local car wash.

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He was taught to drive around the same time. Even with hyper-tonic muscles he preferred to drive standard cars. His favorite sport, believe it or not, is drifting, a style of racing using a driving technique where the driver intentionally over-steers causing loss of traction in the rear wheels or all tires while maintaining control.

My reason for this article is the years of planning and preparations that goes on to get to this very point. In 2009 we were making all the preparations for Stephan's graduation announcements, class ring, pictures, celebration plans, and much more. Then Graduation Day arrived, I went thru a roller coaster of emotions. I felt like I was on a mountain top singing to the world how proud I was! He beat all the odds, faced many challenges and persevered. Never teach *NO you can't* and never learn to say *NO I can't*.

The child that acquired an illness was told he would never learn or walk again, we, his family, witnessed him walk across the stage, accept his regular diploma and owned it. He went on to college and works as a mechanic at a car dealership and continues with his education.

To see this happen takes a lot of work 24/7, no joke. School years pass so fast, and it is up to you to get creative and plan their educational future from early on. It is important that your child goes to IEP meetings and learn advocacy skills from a very young age. Begin with having conversations with all involved in what you like to see your child achieve, have dreams, plan it, and monitor the progress.

It's also important to learn about all supporting resources in your community that is available to support your child's dream. FHF has a transition facilitator that can help with this process.

When your child is ready to exit high school and is planning to attend college, take advantage of using "Louisiana College Guidebook for Parents and Students on Higher Education and Disability" guidebook as guidance. This can be found at: <http://fhfjefferson.org/Images/Interior/resources/education/louisianacollegeguidebookforparentsandstudents.pdf>

So, now you know why "My Favorite Time of the Year is the Month of May" it was the end of a long journey and the celebration of new beginnings. I know this long road all too well and how special it is to make the finale preparations for transition from high school to many new roads, so hats off to you and your son's/daughter's future endeavors! ~

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