



INDEPENDENTLY YOURS

● Summer 2011

DuPage Center Hit Hard Due to State Payment Delays & Funding Cuts

With the State being in such financial disarray, many state funded agencies are not only losing much needed grant funds to run basic programs and services, but are not receiving payments for services already rendered.

The new fiscal year begins on July 1, 2011. Many state vendors, including DCIL, have been told that the beginning of the year payments will be delayed. Further, payments as far back as May could possibly be held up until December of 2011, if not longer.

If the monies do not begin to flow through soon, our Center as well as many other state funded agencies, may be in jeopardy of closing its doors.

To add to the stress of an extremely slow payment process, funding cuts to next year's programs and services have become extreme.

With the new fiscal year upon us, DuPage Center for Independent Living, like many other Centers for Independent

Living, are still awaiting word on just how extreme those cuts will be.

To date, we do know that our Community Reintegration Program (CRP) is slated to be cut by 49% and our Independent Living and Home Services Programs will be reduced anywhere from 1% to 6%. This is extremely devastating to an already modest budget.

As a result of the slow payments and reduction in grant monies, the Center has been forced to lay off one full time staff position and reduce the hours of the rest of its employees. As of June 27, 2011 the New Center hours will be 9:00 am to 4:00 pm, Monday through Thursday, & Friday from 9:00 am to 1:00 pm.

This is a travesty! We need your help! Please contact your legislator today and express your concern over the lack of services and funding cuts.

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**New Center Hours:
Monday through Thursday
9:00 am to 4:00 pm &
Fridays from
9:00 am to 1:00 pm**

**Save The Date
Annual Stroll & Roll:
Saturday, Sept 17, 2011
from
11:00 am to 3:00 pm
Herrick Lake Forest
Preserve, Wheaton, IL**

**MR. G.**

AN INTERNATIONAL COMMUNITY REINTEGRATION SUCCESS STORY

*By
Kevin Giefer*

I met with a person known as Mr. G (pictured right) who was a resident of a nursing home in DuPage County. The Social Worker there put me in contact with him. The Social Worker at the nursing home explained that Mr. G. was Ethiopian and did not speak English very well. So, with myself being a person who is hard of hearing I thought how will this work? Well, the challenge began! He wanted to move into the community and it was my job to provide him the opportunity to determine if he was eligible for the Community Reintegration Program. It was game on!

The first step of the process for eligibility is to obtain medical records and sign releases of information so the State can determine if the consumer is eligible for the Community Reintegration Program. Also the consumer needs to have an adequate amount of monthly income to afford an apartment after the State pays the first months rent. Mr.G informed me that he receives \$674.00 per month in Social Security benefits. I told him the DuPage Housing Authority had no Section 8 Low Income Vouchers to give out. This has been a very serious issue in DuPage County as it is very hard to locate affordable and accessible housing without a Section 8 Voucher. He wanted to find an apartment and get out of the nursing home as soon as possible. He was very determined and resourceful and called apartment complexes inquiring about rent. He kept focused and thought that maybe his brother could move in with him and also become his Personal Assistant. Mr. G. ran that suggestion by me and I thought it was great. He just needed to find a two bedroom apartment, get case approval, and hire a Personal Assistant.

I received the medical documentation and processed the mountain of paperwork that is involved and sent it to the Sate for review. I also met met with Mr. G and did more paperwork for our Center as well as the required Division of Rehabilitation Services (DRS) paperwork. We learned to work and understand each other and found ways to communicate. The communication barrier was no longer an issue and we forged ahead. Mr. G. created and I wrote his service plan based on his needs. He hired his brother as his Personal Assistant and we were ready to look at apartments.

The DRS office notified me that Mr. G 's case was approved for Reintegration. I told him the good news and we went to look at an apartment that he found on his own. He was accepted with his brother as tenants in a two bedroom apartment in Wheaton, Illinois. He selected furniture and I ordered it.

Time was of the essence as the State Fiscal year was winding down and the DuPage Center had upfront reintegration funds needed to be used by June 30th 2011. Mr. G. moved in on June 1st, 2011. We spent three productive days shopping for home furnishings, food and personal items. He was tired, thankful and very happy to have a new home to live in.

Mr. G. stated that he would like to work on his GED. He wanted to say thank you to all of the staff at the DuPage Center for their assistance. He also wants me to thank the State of Illinois for providing him the opportunity to move in to the community through the Community Reintegration Program.

As of this publication date there are still no Section 8 Low Income Vouchers available at the DuPage Housing Authority. Mr. G. was fortunate to get out of the nursing home as the State of Illinois through the Community Reintegration Program as this program may face elimination or drastic funding cuts next year.

**New Center Hours Beginning
June 27, 2011**

**Monday Through Thursday:
9:00 am to 4:00 pm.**

**Friday:
9:00 am to 1:00 pm.**



Think ZEBRA!

In the world of disabilities, most people think of physical, mental/emotional, cognitive or sensory disabilities such as eye sight or hearing loss. The Story you are about to read, is one that is not only near and dear to my heart, but it is also written by a close friend of mine, who is an advocate in her own right.

Leigh Ann Heenan, Executive Director.

**“When you hear hoof beats,
think zebra not horses.”**

By Janifer Burkhardt



In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras.” Most physicians are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra in the mix. Primary immunodeficiency (IDF) patients are the zebras of the medical world. So IDF says “THINK ZEBRA!” Let’s teach the world about “zebras” while helping promote awareness of primary immunodeficiency diseases. Primary immunodeficiency diseases (PID) are a group of more than 150 different types of often widely misdiagnosed genetic diseases. PID is a classification of genetic diseases where part or all of a person’s immune system is compromised, making it difficult for the body to fight infections. In the United States, more than 50,000 people a year are diagnosed with some sort of primary immune deficiency disease. However, thousands more go undetected.

These diseases are chronic illnesses caused by hereditary or genetic defects in the immune system in which part of the body’s immune system is missing or does not function properly. These diseases are not contagious. For some, the body fails to produce any or enough antibodies to fight infection; while for others, the cellular defenses against infection fail to work properly. Throughout their lives, people with primary immune deficiencies are

more susceptible to infections, endure recurrent health problems and often develop serious and debilitating illnesses. Immunoglobulin (IG) replacement therapy is the primary treatment for PID. The immunoglobulin’s used in IG therapy are made from the blood plasma of carefully screened donors. It is manufactured and purified under strict conditions for safety.

Landon’s Story...

Landon had many problems with recurrent and persistent illnesses since I can remember. Antibiotics were not helping and we were constantly at the Dr.’s office- sometimes I felt like I lived at the Dr.’s Office. He had numerous tests, and was hospitalized with pneumonia on many occasions. Our Doctor referred us to an Immunologist/Allergist, thinking it was something to do with allergies. After many tests, and lengthy explanations, the immunologist told us that our son Landon was having some problems with IGG levels in his blood and titers to vaccines. Landon was diagnosed at about 1 ½ years old with a form of Primary Immunodeficiency (PID) which is specific antibody deficiency and hypogammaglobulinemia. She wanted to try Landon on immunoglobulin, but first we had to get the approval of the insurance company. Due to the nature of Landon’s debilitating illnesses, our insurance company turned us down. This is when our real struggles began, but we did not give up.

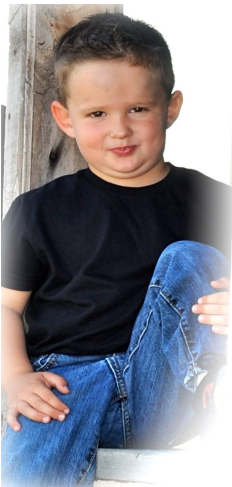


My husband, Mike and I wanted Landon to be able to live a normal life as a child without the fear of being poked with needles and being away from his brothers in a hospital. As a mother, you want to do everything you can for your child to keep them safe and healthy. I began my research on the internet exploring the many different forms of PID and I was amazed, every single thing other parents were going through is what Landon and our family had been going through for almost two years.



Landon's story continued:

We were directed to the Immune Deficiency Foundation, and it has been a blessing for me.



When I was unsure or had a question they had all sorts of resources that I could turn to, and they also have an online community where I could connect with other parents who were going through the same thing we were. While I began to find all the resources and different information I was determined to fight the insurance company. I am Landon's mother. I am his advocate. There is no stronger advocate than a determined mother trying to help her child. I was determined to fight and WIN! I began looking

through my discs of many pictures of Landon while sick and while healthy. But, I also wanted to put a face to his disease and I wanted the insurance company to have to look at his sick face in the hospital with needles, IV's and oxygen. I wanted them to get that by approving this therapy for Landon it was imperative and even life altering for my son and our family.

I began to writing letters to the insurance company and was supposed to show up to the appeal board, however Landon took a turn for the worst and became very ill. I had to rely on my husband to attend the hearing alone, while I cared for our son. He went with a copy of the letter I sent and pictures of Landon, and he listened to what they had to say. Even though our insurance company still did not want to approve the expensive therapy, I can say that we are forever thankful for the "Brotherhood" of the IBEW who overturned the appeal and approved the treatment. By approving the treatments they had a hand in helping a sick little boy get better.

Today Landon gets SCIG (subcutaneous immunoglobulins therapy) at home. This is a treatment in which I place two needles in his legs once a week which provides Landon's medicine in order to help his immune system. This process takes about 2 hours to do and for a child seems like an eternity. We preferred to complete the treatments at home as opposed to the hospital setting with an IV because home is a place of comfort and security for our son. I cannot thank our Immunologist and Pediatrician enough. They are great Doctors and people. We are very lucky & blessed to have them in our lives!

Since beginning the treatments, I can say that Landon has been sick only a handful of times in the past two years and he is growing like a weed.

His smile is infectious and he has a character of his own. If you ask Landon what his dream is he says "I want to be a farmer like my grandfather." They say everything happens for a reason, whether it is to prove some point or to show us a direction or a path in life that we should choose. Landon has done that for me numerous times, but since he became sick, it made me look at things in a new light. I desired to become a nurse. I am currently fulfilling that goal and hope to work with and advocate for "The ZEBRAS" of the world!

The Immune Deficiency Foundation has been a huge resource for our family. Because of all they have done, we decided to give back to the foundation that helps with research, education and advocating for people like Landon. Landon's friend Maggie also lives with a form of PIDD, so we have teamed up and have been doing a fundraiser. All proceeds of the bracelets and t-shirts sold are donated in honor of Landon and Maggie. Maggie and Landon are the "Zebras" of the world. So "THINK ZEBRA!"

Please visit www.primaryimmune.org for more information or to see how you can support IDF. The Immune Deficiency Foundation is a non-profit 501(c)(3) organization. You can learn more on the signs & symptoms as well as make a gift online at www.primaryimmune.org/zebra. Be sure to check off the "THINK ZEBRA!" button and put my name under "Referred by" so IDF knows that **Landon Burkhardt and Maggie Stuebinger** sent you to the website.

Thank you for supporting us
"ZEBRAS" and If you are not in the position to donate funds to the IDF you can always donate blood- it's free!



THINK ZEBRA! to make a difference!



Staff Corner



**Youth Services Coordinator
Chris Ludwig**

Chris Ludwig holds a Bachelors and a Master's degree in English from Eastern Illinois University. For the past 6 years Chris has worked with Ability Links working on the employment opportunity website for job seekers with disabilities and their prospective employers. The services I provided while working there revolved around helping those looking for work to construct and refine their resumes and to keep on top of any employment opportunities that would be a good fit for the clients I was assisting at the time.

As the Youth Services Coordinator, I assist young persons with disabilities and their families along the path towards independence.

Services include:

- Serving as a resource person and specialist with regard to issues on educational rights of children with disabilities (IEP Meetings, etc).
- Providing systems advocacy and serving as a resource to improve educational options for young adults with disabilities.
- Providing social opportunities for Youth with disabilities.



**Staff Assistant
Monica Layman**

Monica holds a Bachelors of Business Administration degree from Loyola University. For the past ten years Monica has worked as a circulation assistant for a local publisher of two national trade publications. Her job was customer service-related and entailed contacting current and prospective subscribers regarding their subscriptions. She also maintained the magazine's data bases and worked on internet research projects for the magazine's editors.

Prior to this time, Monica was a stay at home mom with her two children who are now 17 and 20. She spent much of her time volunteering at the local schools and her church in Carol Stream. She is currently Co-President of the women's group at her church and has run and been involved in several fundraisers, most recently a ladies luncheon/fashion show.

As the Staff Assistant, Monica's duties will include Information and Referral calls, Monitoring the Center's ITAC Amplified Phone Program, assisting with general office support as well as fund development.

Medicaid Managed Care

The Managed Care Program is a program for older adults and adults with disabilities who are enrolled in Medicaid but not enrolled in Medicare. Under the program you must pick a health plan and a doctor or clinic as a Primary Care Provider (called PCP) for your medical home. The integrated care program is currently available in the following counties: Suburban Cook, Kane, Kankakee, DuPage, Lake, and Will. Under the integrated care program, a team of providers and case managers will work with you help you reach the health goals that are important to YOU. Your choices are Aetna Better Health and Illini Care Health Plan. With either plan you will have:

1. Choices of doctors, specialists and hospitals within their network.
2. A team of people working with you to help you live an independent and healthy life.
3. Control of your health care, supports and service needs and
4. extra services to promote your health and wellness.

You do not have to enroll if you:

- Are under the age of nineteen
- Receive Medicare
- Are an American Indian/ Alaskan Native (you may choose to enroll voluntarily)
- Are enrolled in a Spend-down program
- Receive temporary medical benefits
- Are in the Illinois Breast and Cervical cancer program
- Already have insurance that covers hospital and doctor visits

How Do I Enroll:

Think about where you get your health care now
Do you want to stay with your doctor or clinic or do you want to pick a different doctor or clinic?

You can find out if a doctor or clinic is in the health plan you want to pick and get the doctor's or clinic's information by calling the Illinois Client Enrollment Broker at 1-877-912-8880 (TTY 1-866-565-8576) or by going online at www.illinoiscebICP.com

2. Pick a health plan. There are two choices:
Aetna Better Health and Illini Care Health Plan
Each plan has PCPs ready to work with you.

3. Enroll. You can enroll three ways:

- **BY PHONE:** Call the Illinois Client Enrollment Broker at 1-877-912-8880 (1-877-565-8576). The call is free. Enrolling by phone is quick and easy!
- **THROUGH A COMMUNITY HELPER** (ie. DuPage Center for Independent Living):

If you are familiar with one of the community organizations on the attached form, they can help you enroll. You can visit us at the Center 739 Roosevelt Rd. Building 8 Suite 109 Glen Ellyn, IL 60137 with any Integrated Care questions. We are open Mon-Thurs. 9:00 am to 4:00 pm and Fridays 9:00 am to 1:00 pm. We have 2 staff members trained to deal with this specific program so don't hesitate to give us a call or come in to the Center to visit us!

- **ONLINE:** Go to the Illinois Client Enrollment Broker's Integrated Care Program website at www.illinoiscebICP.com and click on enroll.

To find out which plan has what doctors "in network" you may contact them individually at:
Aetna Better Health- 1-877-212-2851
Tty # Illinois Relay # 711
www.aetnabetterhealth.com/illinois

Illinicare- 1-866-329-4701
TTY#- Illinois Relay # 711





**Attention:
Future Newsletters to be Available
in Electronic Format Only!**

Due to the State payment delays and budget cuts, DuPage Center for Independent Living will no longer be mailing out its newsletter.

Newsletter Sign up:

Name: _____

We will still keep you informed and up to date through the quarterly newsletter which will only be available on-line at the Center's website: www.dupagecil.org or via e-mail.

E-mail: _____

If you wish to receive the newsletter via e-mail please contact us at:

Subscribe_dcil@att.net with your name & e-mail address or simply fill out the form to the right of the page.

Return To:

DuPage CIL

739 Roosevelt R. Bldg. 8 Suite 109

Glen Ellyn, IL 60137

Save the Date!

Saturday, September 17, 2011

The DuPage Center for Independent Living Presents the

6th Annual Stroll & Roll

Walk/Run to raise awareness and support of the

DuPage Center for Independent Living!

Plus a Fabulous Silent Auction

11:00 am to 3:00 pm

Herrick Lake, Wheaton, IL

Call the Center for more details.....630-469-2300 v/tty



THE DUPAGE CENTER FOR
INDEPENDENT LIVING

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