Sean O’Donnell “Pays it Forward”

Less than a week after becoming the second scholarship winner to earn his pilot’s certificate, Sean O’Donnell of Philadelphia was negotiating the purchase of a specially-adapted Sky Arrow, the same aircraft model used during his training. That was during EAA AirVenture 2007 in Oshkosh, Wisconsin, the site of Sean’s month-long training that led to him passing his checkride on the opening day of aviation’s largest event.

O’Donnell’s dream of flying began well before the motorcycle accident that caused his paralysis nearly 13 years ago. But it was a dream put on hold until he learned of Able Flight’s scholarship program and the availability of the Italian-made Sky Arrow 600 LSA, an airplane that can be ordered with factory-installed controls that enable it to be flown entirely by hand. Buying a plane of his own would be a great story in itself, but it goes far beyond that. With his Sky Arrow, Sean is opening Philly Sport Pilot at historic Wings Field just a few minutes north of Philadelphia.

“When I was awarded the Able Flight scholarship, I truly felt that it was a fantastic gift,” said O’Donnell. “But I also felt that I was charged with a duty: That duty was to work as hard as I can to pass this gift onto others. The best way that I could do that was provide flying resources for people with disabilities in the Northeast, particularly, Philadelphia.

“My first hope is to provide safe, quality training for all those who can achieve it. I don’t want to see someone who is completely capable of being a good pilot, like I was, stopped by an issue like mobility - which we are smart enough to get around. My second hope is to see Able Flight thrive and help provide them with the resources they need to accomplish their mission. It is a team effort and something I believe in.”

“Sean’s decision to create his own flight school is an outstanding example of “paying it forward”, said Charles Stites of Able Flight. “He has created a second training location where we can send Able Flight scholarship winners, and in fact, we already have a young man who was paralyzed in a motorcycle accident a little over a year ago, scheduled to attend. Sean’s been very successful in his own life, never allowing personal challenges to stand in the way of his many achievements. For years, he has served as a role model for others facing similar challenges, and he’ll do the same for our scholarship winners who attend his school.”

Working in conjunction with Montgomery County Aviation, the largest flight school in Philadelphia, Philly Sport Pilot opened in February, and provides training for Sport and Private Pilot Certificates for student pilots with or without a disability.

“My advice to anyone, disabled or not, is to give flying a try. Men and women for ages have dreamed of being able to fly, and we are fortunate enough to live in a time when it is possible and accessible to everyone. Even one hour at the controls of an airplane give you a better understanding of something that is often mysterious and unknown. For the disabled, it is your chance to be just like everyone else for a few moments. Once you’re in the airplane, you are only a pilot, like every other pilot before you and after you. It is a truly unique opportunity.

For more information on Philly Sport Pilot, contact Sean at www.phillysportpilot.com.
RESEARCH & EDUCATION

SPINAL CORD INJURED INDIVIDUALS WITH MODERATE TO SEVERE SPASTICITY NEEDED FOR CLINICAL TRIAL

The Regional Spinal Cord Injury Center of Delaware Valley (RSCICDV) at Thomas Jefferson University and Magee Rehabilitation Hospital is interested in testing new drugs which may benefit persons with spinal cord injury. Jefferson and Magee are participating in a large clinical study to evaluate an investigational medication that may improve spasticity in individuals with incomplete chronic spinal cord injury. We are looking for participants who:

- Are between 18 – 70 years of age
- Have an incomplete spinal cord injury for more than 6 months at a level between C4 and T12
- Have moderate to severe spasticity
- Be willing and able to stop other antispastic/muscle relaxant drugs

The study will be double blind and placebo-controlled, which means that some individuals enrolled in these studies will receive a placebo (or inactive substance) during the study, and will not receive drug at any time during the study. Neither the investigators nor the study participants will know who is receiving drug or placebo until after the end of the study.

If you are interested in participating in this study, some simple questions over the phone will help to determine if you are eligible. Overall participation in the study will include 8 outpatient visits to the SCI Center at Thomas Jefferson University Hospital over a period of 6 weeks. Each of these visits will require approximately 4 hours of your time. You will be paid for travel costs and free valet parking will be provided. Your participation in this research study is voluntary and, you can end your participation, if you wish, at any time.

To see if you qualify, please call Marilyn Owens, R.N. at (215) 955-6579.

RESEARCH PROJECT FOR THE RSCICDV

Starting this Spring, the combined efforts of SCI Center staff from both Thomas Jefferson University and Magee Rehabilitation Hospital are supporting a new multicenter study entitled “Investigation of Assistive Technology for Mobility used by Individuals with a Spinal Cord Injury”. Working together with SCI Centers in Pittsburgh, Georgia, Chicago, Washington DC, Ohio and Northern New Jersey, we are investigating the impact of policy changes on customizability and features of wheelchairs, and the number of working wheelchairs an individual owns. To collect this information, we are looking at the specifics of an individual’s wheelchair usage, relative to the type of wheelchair they were provided, the amount of wheelchair breakdown, the skill of using the wheelchair and quality of life measures of participation for the individual using a wheelchair for primary mobility. Since it has been shown that reintegration into society following a disability depends on access to appropriate and adequate assistive technology such as wheelchairs, we hope to investigate the effects of the types of presently supplied wheelchairs and how they may be contributing to a person’s functional limitations, even more so than the person’s disability itself. The information (or data) collected over the next 4 years may then be helpful in effecting policy change, relative to prescriptions for wheelchair mobility equipment.

If you are interested in participating or would like more information, please call Mary Patrick, RN, RSCICDV Project Coordinator, at (215) 955-6579.
YOU ARE INVITED!

The Tuttleman Family Foundation presents the

Dr. Guy Fried Educational Seminar with the internationally known scientist

Wise Young, MD, PhD
Magee Rehabilitation Hospital
Wednesday, June 4, 2008
1:30 - 3:00 pm

Combination Therapies of Spinal Cord Injury and Clinical Trials

Objectives:

• Describe the current state-of-the-art spinal cord injury research
• Discuss clinical trials that are ongoing, and plans to test medical therapies in the US and internationally

Former patients and families are welcome to attend. To register, call (215) 587-3055 or register online at MageeRehab.org.

Dr. Wise Young, founding director of the W.M. Keck Center for Collaborative Neuroscience and a professor at Rutgers, The State University of New Jersey, is recognized as one of the world’s outstanding neuroscientists. Well-known as a leader in spinal cord injury research, Dr. Young has participated in numerous avenues of research related to spinal cord injury regeneration, pharmaceutical or clinical interventions, as well as outcome measurement. Dr. Young is known internationally for his work to upend concepts that spinal cord injuries are permanent, to refocus research efforts and to open new vistas of hope. He has been featured in many publications and media/TV specials as a well-known leader in spinal cord injury research. Dr. Young has also been recognized by multiple organizations with distinguished awards relative to his commitment to finding a cure, and advocacy efforts.

PAIN STUDY FOR SCI AT JEFFERSON/MAGEE

The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University/Magee Rehabilitation is currently taking part in the SPINAL research study. This study will test to see how well an investigational drug works for your pain associated with your traumatic spinal cord injury.

We invite you to consider participation in the study if:

• You are at least 18 years old
• You have pain associated with your traumatic spinal cord injury
• You are dissatisfied with your current pain treatment.

• You are willing to come to our clinic for 8 visits over a 16 week period.

Participants who qualify will receive at no cost:

• Study related physician visits
• Study procedures and lab testing
• Study medicines
• Additionally, you may receive compensation for your time.

RSCICDV will begin recruitment in August/September. If you are interested in learning more about this research study, please contact Mary Patrick, R.N., RSCICDV Project Coordinator at (215) 955-6579.
ONGOING RESEARCH OF THE RSCIDV

Current

1. A four-week, prospective, randomized, double-blind, placebo-controlled trial to assess safety, tolerability, Pharmacokinetics and preliminary efficacy of AV 650 in patients with spasticity due to spinal cord injury. Sponsor: Avigen


3. A phase I/IIa dose-ranging study to evaluate the safety, tolerability, and pharmacokinetics of BA-210 and the neurological status of patients following administration of a single extradural application of Cethrin® during surgery for acute and cervical spinal cord injury. Sponsor: BioAxone Therapeutics Inc.

Completed Clinical Trials


2. A phase II, double blind, placebo-controlled, multicentered study to access the efficacy and safety of HP184 at 100, 200, and 400 mg doses administered orally once daily for twenty-four weeks in adult subjects with chronic spinal cord injury. Sponsor: Aventis Pharmaceuticals.

3. Peripheral denervation following spinal cord injury (Using MRI to study nerve function following spinal cord injury). Sponsor: American Paraplegia Society


SPINAL CORD SOCIETY

The Spinal Cord Society is a large grass roots organization with thousands of members throughout North America and other countries. Its goal is cure of chronic spinal cord injury paralysis. The Spinal Cord Society puts 100% of its funding into research for the cure of spinal cord dysfunction. The Spinal Cord Society meets at Magee Rehabilitation Hospital on the 6th floor at 1 pm on the first Saturday of every month.

If you would like to support this research, consider attending one of these meetings.

For more information, please contact Chris Cellucci at cellucci@ursinus.edu or (610) 296-7429, or Dennis Ledger at dledger@csc.com or (856) 468-4401.
We are always looking for new topics. If you have an idea for a topic or would like more information, please call Marie Protesto or Sonya Dibeler at peers@mageerehab.org or (215) 587-3174.

**SCI FAMILY PEERS**

Magee Rehabilitation welcomes Ruth Black, MSS,LCSW in her new position as Family Mentor Coordinator for the SCI program. Ruth was a Staff Social Worker at Magee from 1987-1991. She then joined the Social Work team at duPont Hospital where she was employed for thirteen years.

Ruth is looking to expand the Family Peer Support Program. She is looking for family and loved ones of previously injured SCI patients to volunteer to be Family Peer Mentors.

Family Peer Support is a group in which specially trained families who have experience with a spinal cord injury help others who share their struggles. Family members and significant others of individuals who have had a spinal cord injury are encouraged to attend. Inpatient and outpatient families are welcome. Family Peer Counselors offer reassurance, support and helpful practical tips.

This group meets on the third Wednesday of every month at 6 p.m. in the 5th floor lounge on the Spinal Cord Injury Unit at Magee Rehabilitation Hospital. Assistance is also available by phone if you cannot attend the meetings.

For more information or to become a Family Peer Mentor, please contact Ruth Black at (215) 587-3174 or rblack@mageerehab.org.

**SCI PEERS, sharing experiences**

The SCI-Peer Consultant Group provides individuals who have suffered a SCI the chance to learn from those who have rehabilitated following such an injury.

Magee can match peers based on injury level, social situations, age, gender, marital status, recreational interests and vocational experience.

To request a peer consultation, or to volunteer as a mentor, contact Marie Protesto or Sonya Dibeler at peers@mageerehab.org or (215) 587-3174.

**SCI RESOURCE & SUPPORT GROUP**

This group provides education, recreation and support opportunities to individuals with spinal cord injuries. Traditionally, meetings are held at Magee on the second Thursday of every month at 6 p.m. in the Second Floor Conference Room. However, social outings are scheduled based on availability and pricing.

We are always looking for new topics. If you have an idea for a topic or would like more information, please call Marie Protesto or Sonya Dibeler at (215) 587-3174, or e-mail peers@mageerehab.org.

**WOMEN’S DISABILITY SUPPORT GROUP**

To help women with spinal cord dysfunction explore their thoughts and feelings about life with a disability, Magee provides a support group each Monday afternoon. This group addresses topics such as relationships, career issues, intimacy and sexuality.

For more information about this group, contact Marie Protesto or Sonya Dibeler at peers@mageerehab.org or (215) 587-3174.
Staying active is the key to a happy and healthy life. Magee Rehabilitation and other Philadelphia agencies offer numerous specialized recreation opportunities at little or no cost. For more information on additional Magee sports and other specialized recreational opportunities, please consult the Magee Recreation Resource Guide.

For a copy of the resource guide and more information on any of Magee’s sports teams, please email Anna Martin at amartin@mageerehab.org.

### WHEELCHAIR SPORTS

#### MAGEE WHEELCHAIR SPORTS TEAMS

<table>
<thead>
<tr>
<th>SPORT</th>
<th>DESCRIPTION</th>
<th>SEASON</th>
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<tbody>
<tr>
<td>Magee Eagles Wheelchair Rugby Team</td>
<td>Quad Rugby is a unique, competitive sport for individuals with quadriplegia. The game is played on a basketball court by four member teams using a volleyball. The objective is to carry the ball across the opponent’s goal line.</td>
<td>The season runs from October through March. Each year the team competes in tournaments all along the East Coast and regularly qualifies from the national play-offs.</td>
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<tr>
<td>Magee Sixers Spokesman Basketball Team</td>
<td>The Magee Sixers Spokesmen are one of 18 teams nationally that are affiliated with their local NBA teams. The Sixers Spokesman are nine-time Mid-Atlantic Conference Champs! New players are encouraged to join our developmental team.</td>
<td>The season runs from October through March. The team competes in games and tournaments along the East Coast! The Magee Sixers are ranked in the Top Ten Teams in the country.</td>
</tr>
<tr>
<td>Magee Kixx Power Soccer Team</td>
<td>A new sport for power wheelchair users, played on a basketball court with four players who attack, defend and maneuver an oversized soccer ball in an attempt to score points on a goal.</td>
<td>The team is encouraging the growth of other teams in the area to allow for local competitions.</td>
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<tr>
<td>Magee Freedoms Tennis Team</td>
<td>Wheelchair tennis can readily be enjoyed with able-bodied friends. The sport follows the rules of the U.S. Tennis Association with one exception—the wheelchair tennis player is allowed two bounces instead of one.</td>
<td>The season runs from March through October. Each year the team competes in tournaments throughout the country.</td>
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COMMUNITY PROGRAMS

THINK FIRST

To help prevent disabling head and spinal cord injuries among children, teens and young adults, Magee’s Think First Program holds dynamic presentations at schools. Our program is part of the nationally coordinated Think First program. Presentations consist of injury prevention lessons and testimonials from adults with disabilities.

If you have a spinal cord injury or brain injury and are interested in changing behaviors and saving lives, please consider joining Think First and speaking to students. Since Magee values your experience we will reimburse you for your time.

If you are interested or know of a school that would like to host one of our assemblies, please call Joe Davis, Think First Coordinator, at (215) 587-3400.

Alcoholics Anonymous

This group meets every Sunday at 6:30 p.m. in Magee’s Cafeteria.

For more information about AA, please call Joe Davis at (215) 587-3400.

HIREABILITY

hireAbility is a nonprofit organization dedicated to helping individuals with disabilities seek employment throughout Philadelphia and South Jersey. Headquartered at Magee Rehabilitation Hospital with offices in Blackwood, NJ, hireAbility works with a number of area businesses and receives daily updates on open positions in the region.

hireAbility offers customized job search assistance.

The organization also partners with various community agencies that provide computer and assistive technology training as well as other skills training. In addition, hireAbility can refer you to organizations that provide housing programs, transportation information and other services designed to help individuals return to work.

For more information, please call (215) 587-3080.

LEGAL CLINIC FOR THE DISABLED

The Legal Clinic for the Disabled provides free civil law legal services to low-income individuals with physical disabilities.

Located at Magee Rehabilitation Hospital, the nonprofit organization can help with cases involving wrongful evictions, consumer fraud, employment discrimination and failure to comply with the Americans with Disabilities Act of 1990. Other serviced include estate planning and benefits counseling.

The Legal Clinic would like to work with you regarding any of the above issues.

For more information about direct representation of outreach programs, please call (215) 587-3350.
PATIENT FAMILY RESOURCE CENTER AND MEDICAL LIBRARY

Feel free to stop pass our patient and staff learning resource center (library) on the 3rd floor, as it has had a slight face lift. We have tons of interesting fiction, a number of best seller books including notable books that made Oprah Winfrey’s Book Club list. There are about 600 leisure/romance/mystery novels to choose from as well as a broad selection of relevant professional periodicals. You may have noticed that we have three computers spaced just right for patient, visitor and staff access and to supplement these resources, we also have an assortment of VHS tapes and DVDs that are available to you for your use either here or at home.

Our book club began in October in the library. This is an exciting time of change for our library and we would like your participation to help this book club initiative and make it great in every way possible. Make the library your place of rest, relaxation, comfort and enjoyment away from the rut of the day-to-day activities of Magee. Volunteers and Venus Bradley are on hand to assist you as best we can with research requests, scheduling the reading room, or locating meaningful information.

Also, it is noteworthy to state that the library has flavored coffee available at the low price of 60 cents for an 8 ounce cup. This is our way of making your visit more like home while you read the Philadelphia Inquirer, New York Times or the magazine/book of your choice.

Please allow us the opportunity to provide you with extraordinary customer service and an enviable user friendly environment. You may contact Venus Bradley at (215) 587-3146 with any questions, concerns or suggestions.

THE NEWSLETTER NEEDS YOUR HELP

Are you tired of seeing some of the same things in every newsletter? Here is a sample list of some of the new information we would like to put in the newsletter:

- People profiles – human interest stories on Magee Alumni
- How do I?
- Where do I find?
- Press releases
- Advocacy/Legislation updates

In order to incorporate these changes, we need you to assist with newsletter!

We want to know how you are doing - what have you accomplished, where have you been, and what have you done. You can pass along some tips that have helped you cope with your disability. Maybe you have some ideas for a regular column, have an idea for an article, or are interested in writing an article.

We need your input to make this work! Please contact Sonya at (215) 587-3174 or sdibeler@mageerehab.org.

WEBSITES OF INTEREST

http://hbedelstein.home.att.net - help for disabled artists
www.phillysportpilot.com - disabled and able-bodied pilot training
www.freedomswings.org - soaring for the disabled
CONSUMER ARTICLES

SOARING WITH FREEDOM’S WINGS  Lauren Ostrowski

What if you could experience sensations of flying, brief weightlessness, and ballroom dancing all at the same time? Well, you can. An amazing agency called Freedom’s Wings can allow you to do just that. I remember when I first heard about gliding, I was initially picturing hang gliding, but that’s a different sport. When you "fly" with Freedom’s Wings, you’re in a glider that is essentially an airplane with two seats and no engine.

When I first arrived at the airfield and started talking to everyone involved with Freedom’s Wings, I was amazed by how they were willing to accommodate my needs because of my disability. At the same time, they saw and talked to me as a person, rather than someone with a disability. When it actually became time to get into the glider, there were lots of people around to help, and before I knew it, I was being towed along the ground by the tow plane.

At first, the feeling of being pulled by another plane was really strange, but just when I was getting used to it, the pilot announced that he was going to unlatch the rope. It was right then that I found myself suddenly very concerned with exactly how a plane without an engine would fly by itself. I must’ve been thinking aloud because the pilot started explaining to me that we were going to ride in something called thermals. Thermals are circular air currents, and we rose when we were in them because the air was warm. When we got to the top of the thermal, we floated in circles until we found another one. Apparently this is also the way birds change their altitude, and we were actually gliding in the same thermal as a bald eagle. It was really neat to be that close to something so beautiful and rare. When we were floating in circles, it reminded me of waltzing -- except we were gliding from one thermal to another as opposed to gliding to different areas of the dance floor. There was something else memorable about rising and falling in the thermals: when we moved from warm air to cooler air, I felt weightless for a split second. The idea of leaving everything to nature -- because everything depended on different air temperatures -- was something that I found really freeing.

I was really having a wonderful experience in the air. Then I had a startling thought. Now we have to land a plane without the guidance of engines. By this point, I had a lot of faith in my pilot, so I decided to ask him. He said that the temperature of the thermals really determined how soft the landing would be. I found myself being very thankful that I was wearing a harness in preparation for what I thought was going to be a rough landing. I was very wrong. We touched down to the ground very gently and coasted along the field until we came to a stop.

After the short trip through the landing field, we took some pictures so I could remember the experience. I found myself immediately wishing that I could go again. There is nothing like gliding -- it’s really a way to fly away from reality for a short time. I would recommend it to anyone who wants to see how 20 minutes can change their life.

FREEDOM’S WINGS INTERNATIONAL

Freedom’s Wings International (FWI) is a non-profit organization run by and for people with disabilities. They provide the opportunity for those who are physically challenged to fly in specially adapted sailplanes.

Upcoming events:
May 31, 2008 and June 1, 2008

Freedom’s Wings will offer free introductory rides to interested disabled individuals. The event will be held in conjunction with the Philadelphia Glider Council at their airport in Hilltown, PA located approximately 40 miles north of Philadelphia. Visit their website www.freedomswings.org for directions.

Interested participants should contact us at (800) 382-1197 to reserve a time slot for a 20-minute ride. There are only a limited number of flights available so call now!
TRAVEL TIPS, PART 4 - EUROPE???......YES, YOU CAN!

Mark Chilutti

One of the biggest misconceptions out there is that Europe is not a great place for those of us with disabilities to travel. That could not be farther from the truth!

I have had the pleasure and opportunity to visit several places in Europe, including London, Paris, Monaco, Madrid, Barcelona, Rome and Naples, and have had a wonderful experience in each. As I always try to do in these articles, let me tell you about some of the behind the scenes stuff that is helpful in making these sort of trips.

We are very fortunate to live in a large city like Philadelphia, that serves as a hub for international travel. This allows us to be able to fly to so many international destinations non-stop. Now I know that they are long flights, typically about 8 hours or so, but, the ability to fly there directly is great.

Typically the flights will leave at night and arrive in Europe in the morning. So, it is important that you plan your day of travel a little differently with regards to eating and bathroom issues. I often reduce what I drink a little bit so I can make it to my destination without having to worry about using a bathroom, or, since the flights are at night, have also at times done the “cathing under a blanket routine” without anyone else really knowing what I was doing.

As always, when you make your reservation please be sure to indicate that you are disabled and be sure to get a seat assignment that will work for you. When you arrive at the airport you need to check in with the agents at your gate and let them know if you will be needing assistance so that they can make the proper arrangements and you will board the plane first.

Just like in the US, you need to ask a lot of questions when you book a room. Not every hotel has wheelchair accessible rooms, and some do not even have elevators, or “lifts” as they are often called in Europe. I have found that I am often more successful if I look at hotels that have been renovated recently and also might have locations in the US. Most of them have websites and you can correspond through email with your questions, which is especially helpful if you do not speak the language.

I have had some funny experiences when I arrived at hotels too, even with the best made plans. In London, the hotel I had booked actually got sold the week before I arrived and the name had changed, making me a little concerned as I wheeled up the block, after a long flight, looking all over for it. I have also had a room with a roll in shower, but no shower chair, and nobody in housekeeping who spoke English. After many different attempts, she knocked on my door smiling, holding a plastic party chair that, though not the typical shower chair I was used to, worked just fine!

I have taken taxis, buses, and trains while abroad with no problem. The funny thing is that I can’t tell you the last time I have been in a bus or train in Philly, but they all worked just fine for me in Europe. Staff members at the hotels have been helpful with lining up transportation, providing maps, etc.

Most of the major cities have curb cuts and navigating the streets has been just fine. People are always helpful, so if I got to a corner without a curb cut, we did not need to speak the same language to figure out how to get me down the curb. Same thing goes if I came to a store or restaurant with a small step. But, one of the favorite things to do in Europe is just sit at an outdoor café and people-watch, which is fun and easily accessible!

One of the other nice things is that so many of the places I visited had special entrances for the disabled, and many do not charge us. After buying a pass that got me in to all of the museums in Paris, and never having anyone ask to see it when I entered, I finally learned that admission for the disabled is free.

In Rome, when visiting the Vatican, my taxi driver, who spoke very good English, had me wait in the car while he approached the Swiss Guards to see where the best entrance was for me. In Monaco, while watching the changing of the Guards, the security officers saw me in the crowd and brought me to the front, in front of the roped off area. The Eiffel Tower has an elevator, the London Eye is fully accessible, there is also a special entrance at Buckingham Palace. Even while visiting the Coliseum I was able to get around and see things that were an amazing part of history.

Some of my trips to Europe have been long weekends, but the best one was on a Mediterranean cruise. The ship was great as far as accessibility issues, and it allowed me to wake up in a different city or country without having to pack my bags. Plus, I knew that no matter what I did during the day, I was returning to my room, able to use the bathroom, take a shower and be comfortable.

I am always amazed how too many people tend to place the limitations on themselves, and are afraid to see what is possible in the world. We CAN travel and have great experiences, and can visit just about anywhere with the proper amount of planning.

Spend some time on the internet, find a new place to go to, and, even if it takes 8 hours to get there; GO FOR IT!