



Dear CARD Families,

Thank you again for all your unwavering support to FAU CARD. It has been wonderful to meet so many of you at many of our events. You are truly an inspiration to all of us!

I am excited to introduce the newest member of the FAU CARD team, Noelle Balsamo. Noelle will be working out of the Port St. Lucie office and providing services to Martin and Okeechobee Counties. She comes to us after working as a behavior specialist and teacher for the Massachusetts public school system, where she worked with students, families and professionals providing ongoing consultation, support and teaching. She is an incredible addition to our team!

FAU CARD is sponsoring its 1st Annual Autism Awareness 5K Race and Walk in Sewall's Point in Martin County on April 27th with on site registration at 7am and the race beginning at 8am. We are encouraging all of our northern Palm Beach and Treasure Coast families to come and have fun. For details, please see the event flyer on our website.

Please plan on attending, and encouraging your child's teacher and support staff to attend, our Summer Academy on July 29 and 30. This free event will be held at the FAU MacArthur Campus in Jupiter in the Lifelong Learning Center from 9:00 AM - 4:00 PM. We are very excited to host Dr. Peter Gerhardt, a national expert on autism and transition, along with Dr. Mary Lou Duffy and several other exciting speakers.

The FAU CARD 4th Annual Wings of Hope Cocktail Reception was held on February 28th at the Boca Raton Museum. The event was a huge success and garnered over 150 guests and friends of FAU CARD. I want to thank the countless number of volunteers and sponsors. This event honored Fran and Joe Eppy for their longstanding support and dedication to the Autism community. Thank you also to Glen Stein for serving as Master of Ceremony and Jordan Stein, Sam Rogerson and Lloyd Bucher for their inspiring words. Finally, I want to thank the tireless and hard working FAU CARD staff, Wings of Hope Committee members and James Kay for serving as Committee Chair for all their hard work, dedication and countless hours contributed to make this event a success. Thank you all!

On Saturday, April 13th, we hosted our 7th Annual Family Connections Conference at the FAU MacArthur Campus in Jupiter. This event featured a panel presentation of 14 early childhood through adult non-profit and governmental agencies along with John Miller, an adult on the spectrum. Additionally, the conference hosted 4 breakout sessions addressing Family and Community Inclusion, Picky Eaters, Transitioning to College and Seizure Disorders. Lunch was provided by Life Concepts, an innovative life insurance company. The event was very well attended and the feedback was overwhelmingly positive.

Have a wonderful summer! I hope to see you at some of our events.

Maryellen Quinn-Lunny, Ed.S. Director



Camps & Programs for Special Populations

The 2013 summer camp list has been updated and is now available. You may access the list on our website, www.autism.fau.edu.

Please note that this compilation of summer camp providers is for informational purposes only. Contact the provider directly for more information when determining if a camp or program is appropriate for you, your child, or family member.

Palm Beach State's Summer Youth College offers a variety of classes for children of all ages. Please click on the respective link for more information.







Lake Worth- www.palmbeachstate.edu/syc/lake-worth



Palm Beach Gardens- www.palmbeachstate.edu/syc/summer-youth-camp-pbg.aspx





Executive Director's Update

Wings of Hope, one of FAU CARD's annual fundraising event, was a huge success. Held on February 28th, this year's event was a Mardi-Gras themed reception with live and silent auctions at the Boca Raton Museum of Art.

Due to state budget cuts over the years, we use essentially 100% of our state grant to cover staff salaries. All other expenses, such as phones, travel, mailings, and books, are supported by money raised from Wings of Hope, our 5K race/walk and by donations. Without these funds, we simply could not continue providing the services we now provide. The generous donors and attendees for these events are the life-blood of FAU CARD.

This year's Wings of Hope honored Joe and Fran Eppy, who have helped us for many years. Glen and Tricia Stein and First Capital provided a generous sponsorship. James Kay served as the Chair of the event and was so important in helping all the pieces come together. To all the members of the event committee, I want to extend my most sincere gratitude.

We have a legislative request for additional funding and have worked with many CARD supporters to let our representatives understand the value to the state of increasing CARD services. We remain hopeful of receiving more money. Right now, our fundraising and the wonderful people and business that help us are the key to our continued success.

For more information, please contact me at <u>iscott@fau.edu</u>.

Jack Scott, Ph.D. Executive Director





MEDICAL UPDATE

Current Hot Topics in Autism

Judith Aronson-Ramos, M.D.

In March 2013, the CDC National Health Statistics Report published a follow up study to an early publication of parent reported autism spectrum disorders from 2007. The current study, gathered data from several hundred households. Caregivers were asked if a family member had a diagnosis of ASD (autism, PDD-NOS, or Aspergers). The findings showed an increased incidence of 2.0% (1:50) vs. the original study from 2007 of 1.16 % (1:88). The ratio of boys to girls remained unchanged at 4:1. The largest increase was in children with ASD who had milder symptoms. This may reflect the increased awareness of ASD. Hopefully, with the new 1:50 number we find more attention focused on services. A link to the article can be viewed here: http://draronsonramos.com/wp-content/ uploads/2012/10/CDC-National-Health-Statistics-Report-March-20131.pdf.

A second study published in the Journal of Pediatrics examined the effects of vaccines on autism. Though many are likely to view this study with skepticism, it is unique in its thorough design and serious examination regarding the theory that there is an increase exposure to more antigens (foreign substances) in the current vaccine schedule. What the study showed was there is no correlation between the number of antigens a child received and the presence of autism. They reviewed the number of vaccines received in a day, as well as over the course of several years, and still found no correlation. This is the latest of approximately 20 studies finding no correlation between vaccines and autism. This study is the first to consider, not just the number of vaccines children receive, but also a child's total exposure to the antigens inside the vaccines which trigger the immune response.

The study was aimed to address the concern that children are receiving more vaccines today which is "overwhelming" the immune system resulting in adverse effects. Today's children receive vaccines for 14 diseases in early childhood compared to 9 diseases two decades ago. However, this study showed that the actual number of antigens in vaccines currently are fewer (e.g., the current has 4 antigens vs the previous, which had 3,000). Additionally, in comparing the developmental profile of children fully vaccinated and on schedule with those who were not, there were no differences in the occurrence of autism spectrum disorders. Currently 10% of parents decline vaccines for their children making this an important and reassuring study. You can read more about the latest study here: www.usatoday.com/story/news/nation/2013/03/29/

www.usatoday.com/story/news/nation/2013/03/29/vaccine-schedule-autism/2026617/

Lastly, while information about the relationship between nutrition and supplements and ASD is less clear, there is some emerging research. There are subpopulations of children with autism who benefit from targeted therapy with supplements. There is ongoing research into the metabolic problems that may accompany or play a role in the development of autism. For example, a large study published in Norway showed a definite benefit to supplementation with folic acid during early pregnancy in reducing autism risk. Unfortunately, this data is still new so specific recommendations can not be made. There is some data to show metabolic abnormalities may be more common in regressive forms of autism. It is hard for families to resist trying some of the supplements hypothesized to be beneficial as they are readily available and rarely harmful. However, we do not have clear evidence based guidelines for their use

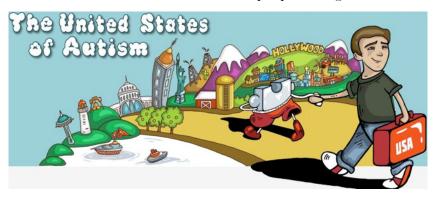
To follow the latest research, you can subscribe to the SFARI (Simons Foundation Autism Research Initiative) newsletter at www.sfari.org.

To learn more about Dr. Aronson-Ramos and provided services, please visit: www.draronsonramos.com

Special Events / Trainings

Screening of "The United States of Autism"

Join us as we host this one-time only screening of The United States of Autism. This documentary is based on the quest of one man who undertook a 40-day journey across the American landscape to find answers for his family and son. With interviews that include the widest spectrum of backgrounds, each conducted in the participants' original language, the film weaves a broad and compelling tapestry across the spectrum of American life in all its faiths, disparities, colors and cultures. It is a story about the best days that still lie ahead for our nation, the families, and the people who give America its heart.



When: May 22, 2013 7:00 - 9:00 PM

Location: Muvico Parisian 20 & IMAX, 545 Hibiscus St., West Palm Beach, FL 33401 25% of all proceeds go to FAU CARD

Tickets must be reserved in advance.

Please visit: www.tugg.com/go/0pqzcc before May 15 to reserve your ticket!

Summer Academy

The 2013 Summer Academy, sponsored by FAU CARD, will be held on July 29th and 30th at FAU MacArthur Campus, Jupiter in the Lifelong Learning Center. Featuring Dr. Peter Gerhardt, a national expert on autism, adults and transition, it is our hope that parents will be inspired and take away strategies to increase successful transition from pre-school to elementary school, elementary to middle school, middle to high school and from high school to post secondary options. The conference will also feature breakout sessions to address early childhood, sexuality, research on evidence-based practices and more.

Boca Raton & Treasure Coast Groups	Date	Time
Adults with an autism spectrum disorder ages 18 and older are welcome. The group meets to discuss issues, problem solve and form friendships. This group meets at the FAU High School or in the community.	5/20 6/17 7/15 8/19	7 - 9 PM 7 - 9 PM 7 - 9 PM 7 - 9 PM
Treasure Coast Adult Group- Community Outings Adults with an autism spectrum disorder ages 18 and older are welcome. The group will meet at various community locations to discuss issues, problem solve and form friendships. Locations will determined prior to outing date. For questions, please contact Cathy Allore, Clinical Support Specialist, at (772) 873-3367 or callore@fau.edu.	5/23 6/27 7/25 8/22	7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM
Parents of children with autism or Asperger's and adults with autism or Asperger's are welcome to attend a monthly meeting held at the Okeechobee Library at 206 SW 16th Street. We will be meeting once a month from 5:30 to 6:45. For more information, check the event calendar at www.autism.fau.edu or contact Noelle Balsamo, Clinical Support Specialist, at (772) 873-3422 or nbalsamo@fau.edu .	5/21 6/25 7/23 8/20	5:30 - 6:45 PM 5:30 - 6:45 PM 5:30 - 6:45 PM 5:30 - 6:45 PM



Trainings & Parent Networking Opportunities All trainings will be available online. Onsite trainings will be held in Boca Raton in Room 411 in the College of Education. Connect to all trainings by emailing card@fau.edu for details.	Date	Time
Development of Leisure Skills- *Online only This online training will teach participants how to increase leisure skills in individuals with autism spectrum disorders from teens to adults.	5/16	6:00 - 7:30 PM
Nutrition & Feeding Challenges Guest speaker, Tania Koerber, Pediatric Nutrition Consultant, will discuss nutrition and feeding as they relate to individuals with autism. Some of the topics include the role of nutrition in childhood development, feeding challenges, nutritional planning and supplementation.	5/24	11:30 AM - 1:30 PM
Managing Disruptive Behaviors Parents and professionals will learn behavior management techniques that can be used in the home and community to prevent and replace problem behavior.	5/31	11:30 AM - 1:30 PM
Teaching Emergent Reading Skills This workshop will address effective strategies to teach reading skills and functional literacy to individuals with ASDs and related disabilities across learning contexts.	6/7	11:30 AM - 1:30 PM
Visual Supports-*Online only Participants will learn about visual strategies to support individuals with autism spectrum disorders at home, school, and in the community.	6/20	6:00 - 7:30 PM

REGISTRATION IS REQUIRED FOR ALL EVENTS.

Trainings & Parent Networking Opportunities All trainings will be available online. Onsite trainings will be held in Boca Raton in Room 411 in the College of Education. Connect to all trainings by emailing card@fau.edu for details.	Date	Time
Parties & Playdates: Promoting Positive Peer Interactions- *Online only This online training will discuss strategies and resources for families interested in facilitating successful social interactions for their child. Topics include setting up successful play dates, preparing for parties and social events, as well as proactive solutions for handling potential conflicts related to these experiences.	6/28	12:00 - 1:30 PM
Understanding Autism Spectrum Disorders Parents and professionals will learn about the characteristics and strengths of individuals with ASD, as well as strategies that can help them be successful.	7/12	11:30 AM - 1:30 PM
Functional Skills to Promote Independence- *Online only Participants will learn procedures and behavioral instructional strategies and routines to teach daily living skills to promote independence and self-help skills.	7/18	6:00 - 7:30 PM



REGISTRATION IS REQUIRED FOR ALL EVENTS.

ALL GROUPS AND TRAININGS ARE SUBJECT TO CANCELLATION DUE TO LACK OF REGISTRATION.
PLEASE CALL **561-297-2055** OR E-MAIL **CARD@FAU.EDU** TO REGISTER FOR EACH EVENT.

FAU CARD NEWSLETTER - PG. 9 **SUMMER 2013** Trainings & Parent Networking **Opportunities** All trainings will be available online. Date Time Onsite trainings will be held in Boca Raton in Room 411 in the College of Education. Connect to all trainings by emailing <u>card@fau.edu</u> for details. Special Presentation: "Sexual Health" This presentation will be conducted by a health educator of the Healthy Mothers, Healthy Babies Coalition of Palm Beach County. Individuals with ASD will be educated on a variety of sexual health issues including abstinence, STDs, contraception, health habits/choices, and 11:30 AM - 1:30 PM 7/19 more. Due to the sensitive nature of this training, participants **must be** 16 years or older. Participants under 18 years of age will require parental permission (given upon registration). This training will not be available for online access. What Works? Evidence-based Standards in Autism Treatment Families and professionals are often bombarded by confusing and often conflicting information about the treatments available to children 11:30 AM - 1:30 PM 8/2 and adults with autism spectrum disorders. This training will help to inform families and professionals on how to make treatment choices based on current information on the effectiveness of different treatments. Introduction to Social Stories/Scripts: How to Write One and When to Use It- *Online only This online training will provide a general introduction to social 8/23 12:00-1:30 PM stories/scripts, suggest appropriate situations in which they can be useful, and explain how to carefully choose language and images to enhance the effectiveness of the stories. Examples and additional resources will be provided.

REGISTRATION IS REQUIRED FOR ALL EVENTS.

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COMMUNITY NEWS

Florida Atlantic University



Autism After 21, a nonprofit 501(c) organization, was formed in 2011 to provide opportunities and services for autistic adults over the age of 21. Founder Michelle Rubin, whose son was diagnosed with autism at age 2, is the driving force behind the organization. She recognized that for many families of an individual with special needs it is difficult to find programs once their children turn 21, even though frequently an individual's needs do not change simply because their age does. Recently, Michelle was the grand prize winner of the Merz Aesthetics and Asclera Stand and Deliver award, a nationwide initiative that honors women who take a stand and make a difference in their communities.

Autism After 21 will offer the opportunity to obtain life skills for independent living to young adults with autism spectrum disorders. They will provide young adults with autism spectrum disorders the life skills training they will need to independently live full and functioning lives within our community. This will be accomplished within a program that would promote physical and mental well-being through therapy, employment, education, housing and social opportunities.

For more information, contact Michelle Rubin at 561-213-5450 or <u>info@autismafter21.org</u> or visit: www.autismafter21.org

IEP Parent Survey

The Florida Department of Education (FDOE) is conducting a survey designed to provide the state with information on how well schools are supporting parental involvement in their child's education. Under the Individuals with Disabilities Education Act (IDEA), each state is required to collect this feedback from parents of children receiving special education services and report it to the federal government annually. Survey results will be used to help schools and districts improve. Don't miss this opportunity!

Go on line to www.esesurvey.com and complete the survey before June 30th.

Si prefiere completar el cuestionario en Español, por favor oprima aquí.

FAU CARD Training Survey

We want to hear from you!

We continue to strive to meet the needs of the families and professionals in our area. In an effort to best identify your interests and needs, the links below lead you to a very short survey in which you can tell us about days, times and topics you'd like for us to offer!

To complete the survey, please visit: www.surveymonkey.com/s/parent_trainings.

Si prefiere completar el cuestionario en Español, por favor visita: <u>www.surveymonkey.com/s/encuesta_padres</u>.



TREASURE COAST COMMUNITY NEWS

Camp ABLE of Martin County

The Able Summer Camp program is offered throughout the entire summer and includes physical games, activities and interaction in a stimulating environment, to include canoeing, swimming, horseback riding, as well as computer and other educational activities in a behaviorally based curriculum.

When: June 5th – August 14th, 2013 8:30am – 4:30pm

Where: Charles Leighton Park 2701 SW Cornell Ave, Palm City, FL

Registration package and payment must be returned to the ARC of Martin County by Friday, May 17, 2013 to ensure a spot for your child. ARC of Martin County is located at 2001 S. Kanner Hwy. in Stuart, FL.

Space is limited and for more information call the ARC of Martin County at 772-283-2525.



Arts for Autism of the Treasure Coast is a program designed to provide individuals with Autism Spectrum Disorders the opportunity to express themselves through art by providing enriching instruction. Individuals with ASD will receive art instruction weekly in low ratio, ASD-sensitive classes.

For more information, contact the program at 772-260-6941 or find them on Facebook at Arts for Autism of the Treasure Coast.

Puzzled Families of Indian River

Puzzled Families is a parent support group that meets to provide support and information for parents of individuals with autism spectrum disorders.

When: 2nd Monday of each month from 6:00 – 8:30 PM

Where: Sun Up Center, 2455 5th Street SW, Vero Beach, FL

Dates: May 13, June 10, July 8, August 12



TREASURE COAST COMMUNITY NEWS

Traveling Barber Service by: Cathy Allore

Hair cutting for my son was always a stressful and anxiety-ridden experience for both my son and me. I was taking him to a friend to cut his hair and, more times than I care to remember, we cleared the barber shop out! The owner was always very easy-going and accommodating concerning my son's challenging



behavior regarding hair cutting. I tirelessly searched for someone to come to my home to cut his hair so that I didn't feel the stress and anxiety of people staring or making judgments about my son's behavior. At one point, I found someone to come to my home and scheduled an appointment only to have her not show up.

I know that this is a challenge for many families who have family members with autism and I am happy to announce a new traveling barber service that will be available throughout the Treasure Coast. Jamie has been working as a trained and licensed barber for 18+ years in Martin County. In the past, she cut my son's hair and has been present during the visits to the barber shop. She understands that for some

individuals with autism, hair cutting is a strange and possibly scary experience. Jamie will travel to provide barbering services to your family to help alleviate that stress and anxiety felt by both the individual and the caregiver.

For more information on this service, contact Jamie at 772-215-1580.

Summer Program

Treasure Coast Christian Academy's Possibilities Program in St. Lucie West will be offering a summer program for individuals with autism and related disabilities. The program is designed for students with autism and related disabilities, who would benefit from a curriculum and environment enriched with functional skills for real world application. These skills would include daily living skills, adapted physical education, differentiated academic program, and opportunities for socialization with same age peers in the mainstream population of the school. All curricular resources are adapted and supported with picture symbols for ease of instruction. A leisure skills component is also being utilized as a way to help students learn how to occupy their time in meaningful ways.

If interested in finding out more about the program including dates, times and tuition, please contact the school directly at 772-343-8088 and ask for Anna or visit: www.mytcca.org/possibilities-program.html.



FAU CARD NEWS

Florida Atlantic University

Board Member Speaks to FAU Graduate Students



FAU CARD Constituency Board Member, Michele Weppner, was recently a guest speaker in Dr. Jack Scott's graduate class which focuses on the nature and characteristics of Autism Spectrum Disorder. Michelle spoke to the class about the challenges and successes of being a parent of a child with ASD. The students are classroom teachers seeking their master's degrees and endorsement in ASD at FAU and they found this first-hand experience and knowledge to be extremely valuable as they pursue to further develop their careers.

Dell Tablet Winner!

At this year's Family Connections Conference, we held a free raffle for a Dell Latitude Tablet. Made possible by a generous donation from Dell, this device combines the convenience and mobility of a Windows 8 touch tablet with the productivity of a PC. All family attendees were eligible. The lucky winner was Andrea Abramowitz! We hope you and your family enjoy the new tablet, Andrea!



Project iCAN Funded by Autism Speaks

FAU CARD is the recipient of a Family Services Chapter Grant funded by Autism Speaks. The grant



targets local services that enhance the lives of those affected by autism. FAU CARD was one of five agencies in the South Florida region to receive the grant. Spearheaded by Elisa Cruz-Torres, Clinical Support Specialist at FAU CARD, Project iCAN (Using the **i**Pad to **C**ommunicate and **A**ccess **N**eeds) will

provide training and materials to several lowincome families who have children with impaired communication. Families chosen will be taught how to navigate the iPad and Proloquo2Go, a communication app. We are excited to provide families with the opportunity to become instrumental in teaching their children how to communicate more effectively. Stay tuned for future workshops and trainings highlighting tablet



and app use for individuals with Autism Spectrum Disorders.



ASK EPPY

Establishing Financial Security for You & Your Loved Ones

Fran Eppy

The \$2000 Rule: Your child may not have more than \$2000 in their name at any time or they will not qualify for government benefits! This also means that if they have benefits and end up with \$2000 at any time, they can lose those benefits. Also, there is a 5 year look back on this rule, which means it could take 5 years to get these benefits reinstated. Below, you will find a list of assets to review. You will want to make sure that your child with special needs is not named as the beneficiary of any of these assets. Be careful! Some of these will automatically end up going to the child without you being aware! Any assets to the child will need to be named to a trust that you will create.

You can explore the following **government programs** to see what may fit into your specific scenario.

- Medicare
- · Medicaid
- · Medicaid Waiver
- Social Security Disability Insurance or Supplemental Security Income

Beyond these programs, you are going to need to understand the different kinds of **special needs trusts** available, such as 1st Party and 3rd Party, how they function, and how to fund them most efficiently. You will also need to think about who will be the trustee. A corporate trustee may be a good option to look into.

You will also need to learn about the different *types of guardianship* available and which, if any, are applicable to your situation. Additionally, think about successor guardians for your child. Some types of guardianship are:

Plenary Guardianship

Limited Guardianship

Guardian Advocacy (This was created specifically for persons with cognitive disabilities so be sure to explore this option.)

Additional planning necessities:

You must have a will; otherwise the state will force assets onto your child and thereby disqualify them for their government benefits.

Life Insurance policies are a critical piece of the puzzle and work in many ways. These policies are more cost effective if they are purchased while you are young and healthy. It is highly advisable to enter into this planning early to take advantage of your age and health ratings. They can provide a death benefit which must be assigned to the trust so as not to jeopardize any government benefits. This will, at your death, be the funding for the well being of your child for the remainder of their life. Some of these policies may also help improve the quality of your life now because they may have living benefits. Speaking to a highly qualified planner will be in your best interest to help you make the right product choices. There are many types of insurance and you will need to be well educated to make the right choices.

Long Term Care Insurance is also an important option to examine. If you are caring for a child with a disability and then you become unable to care fully for yourself, who will care for your child? There is a product called "indemnity" that will pay your full coverage each day. This is a bonus because if you are not using all of that money for yourself, a portion could be useful in supplementing the care you will need for your child during that time.

A final note of caution- consult with professionals that are experts in this area. FAU CARD has access to many well qualified experts and can direct you to them.

Eppy Financial Group, Inc. 1000 Corporate Drive 7th Floor Fort Lauderdale, FL 33334

Joseph Eppy, President of Eppy Financial Group is dedicated to helping families with special needs and can be contacted at <u>i.eppy@eppyfinancial.com</u> or by calling 954-689-9476.



CONTACT US

Statewide CARD Toll Free Number: 1-800-9-AUTISM (288476)

FAU CARD Toll Free Number: 1-888-632-6395

Website: <u>autism.fau.edu</u> e-mail: <u>card@fau.edu</u>

Boca Raton Campus

777 Glades Road Boca Raton, FL 33431

Main Line: 561-297-2023

Fax: 561-297-2507

Treasure Coast Campus

500 NW California Blvd. Port St. Lucie, FL 34986

St. Lucie and Indian River Counties: 772-873-3367

Martin and Okeechobee Counties: 772-873-3422

Fax: 561-297-2507

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Thank you!

We would like to express our most sincere gratitude to all of the families and professionals who contributed to our Wings of Hope CARD-i-Gras event honoring Fran & Joe Eppy.



FAU CARD board members & special friends (from left to right): Joe & Fran Eppy, Michele Weppner, FAU President, Dr. Mary Jane Saunders, Joe Cardenas, Glen & Tricia Stein, John Miller, Judi Donoff, & Lloyd Bucher

If you or your organization would like to contribute to FAU CARD, donations can be made out to:

FAU Foundation - CARD

and mailed to our office at:

FAU CARD
Department of ESE
777 Glades Road
Boca Raton, FL 33431

Or visit:

https://fauf.fau.edu/NetCommunity/SSLPage.aspx?&pid=1151