



heart of illinois

Down Syndrome Association

Newsletter

February 2018

Contact Us:

c/o Bethel Lutheran Church
325 E. Queenwood Rd.
Morton, IL 61550
309-712-4852
info@hoidsa.org

The Heart of Illinois Down Syndrome Association, Inc. is committed to improving the quality of life of persons with Down syndrome by providing support, advocacy, and educational opportunities to those individuals, their families and community advocates.

Calendar of Events

2018 Board of Directors

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The Heart of Illinois Down
Syndrome Association, Inc. is a
501(c)3 not-for-profit organization.

- | | |
|--------------------------|---|
| Sun. March 4th | 29th Annual Spaghetti Dinner
11:00am - 6:00pm,
ITOO Hall, 4909 W. Farmington Road, Peoria |
| Mon. March 5th | Board Meeting - 6:00pm
Fondulac Library, East Peoria |
| Sun. March 11th | Young Athletes Practice - 3:00pm
St. Philomena School, 3216 N Emery, Peoria |
| Tues. March 13th | ACCESS March Madness Experience
FREE Event - see page 6 for details |
| Tues. March 13th | Patrick Schwarz: Just Give Him The Whale
9:00am-3:00pm Heartland Community College,
Normal IL. FREE Event - see page 7 for details |
| Tues. March 20th | Young Adults Cooking Class - 7:00pm
Bethel Lutheran Church
325 E. Queenwood Rd., Morton |
| Weds. March 21st | World Down Syndrome Day |
| Thurs. March 22nd | Grandparent's Group Meeting - 6:00pm
Bernardi's Pub, Dunlap |
| Sat. March 24th | HOIDSA Easter Egg Hunt - 10:00am
Northminster Presbyterian Church, Peoria
See page 3 for details |
| Sat. April 7th | Illinois Family Leaders Annual Conference
9:00am-3:00pm Spalding Pastoral Center, Peoria
See page 8 for details |

This newsletter publishes items of interest relating to Down syndrome and other disability issues. The Heart of Illinois Down Syndrome Association, Inc. (HOIDSA) does not promote or recommend any therapy, treatment, institution, professional system, etc. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. We hope to bring together those interested in Down syndrome and attempt to create an optimistic future and attitude. The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication.

Greetings From The President



Inside this Issue

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As we head in to spring there is much happening with HOIDSA. Spaghetti dinner is right around the corner and that is always a great opportunity to see some friends, enjoy some delicious spaghetti, take home a week's worth of baked goods and, if you are lucky, win one of the awesome raffle prizes or silent auction items. I love this event and each year I have the same reaction. I am always so thankful for the friends I have made in HOIDSA.



From my hospital room in the days after Meg was born I spoke on the phone with 2 moms who were further along their journey raising children with Down Syndrome. As I tried to process Meg's diagnosis and all that it meant, both women offered me friendship, support, honesty and perspective in their own ways. The first brought her son (who was about 3 at the time) to the hospital to see us the day after Meg was born. As her little one sat on my husband's lap (and stole his heart), this mom from HOIDSA began to share her experiences, fears, hopes in such a way that I felt she was making sense of all the things I was thinking but could not express. In those moments she helped me to see that although this journey was new and unexpected, I did not have to travel it alone. There would be others to help guide me along the way. The second mom I spoke to had a daughter who was about 7 or 8 at the time. She talked about the impact her daughter had on the other kids in the family and how her daughter was more like her siblings than different. As we spoke the mom looked out her kitchen window, laughed and said "in fact, she's out in the yard giving someone the business right now!" In that moment this mom offered me hope and a sense that while this journey was unexpected, there was going to be laughter and joy. Both of these women will always have a very special place in my heart, because they were the first from HOIDSA to open their hearts and share their experiences.

I love the spaghetti dinner because I know that even though I don't see either as much as I would like, I will see them that first Sunday of March every year. I look forward to those few minutes when I get with each to catch up, see their families, and hear how their kids are doing. I am incredibly thankful for HOIDSA because of these women and so many other amazing people who this group has helped me connect with. As Meg has grown, I have continually found mentors, answers, ideas and support at each step of the way.

I appreciate the education, support, resources and friendship this group provides. I hope that each of you has the opportunity to join us for dinner on March 4th and if you don't please check out another HOIDSA event soon. I promise you'll enjoy the experience.

Anne

March

Janelle Begner
3/1

Chris Bigelow
3/1

Maggie Getz
3/6

Jax Gander
3/11

Dakota Herold
3/11

Benit Roth
3/13

Jared Hicks
3/14

Jessica Pribble
3/15

Willis Leighty
3/17

Nicholas Stuber
3/18

Jack Robison
3/20

Joseph Zimmerman
3/21

Jamie Martin
3/23

Mercy Thacker
3/24

Ashley Wertz
3/26

Trevor Colby
3/27

Lisa Pattelli
3/30

MARCH 21: WDSD SEE THE ABILITY!



World Down Syndrome Day is annually observed on March 21 to raise public awareness and understanding of Down syndrome. Down Syndrome International encourages our friends all over the world to choose your own activities and events to help raise awareness of what Down syndrome is, what it means to have Down syndrome, and how people with Down syndrome play a vital role in our lives and communities.

You are invited to the next GRANDPARENT'S GROUP meeting

Thursday March 22nd

Bernardi's Pub

Lake of the Woods Plaza—12200 N Brentfield Dr., Dunlap

6:00 pm

An informal evening with casual conversation

Questions?

309-241-8195 or

hohimer_home@comcast.net

HOIDSA Easter Egg Hunt

Saturday, March 24th at 10:00 am

Northminster Presbyterian Church

10720 N. Knoxville Ave, Peoria

Contact Renee at
renoslif@yahoo.com or
(309) 453-3115
if you can donate
plastic eggs or candy.



Special Olympics
Young Athletes™

The Young Athletes program is an innovative sports play program for children ages 2-9 with and without intellectual disabilities, designed to introduce them into the world of sports.

All sessions held at

St. Philomena School gymnasium

3216 N Emery, Peoria

3:00 pm – 4:00 pm

Sunday, March 11, 2018

Sunday, April 8, 2018

Sunday, May 6, 2018

If interested in participating or volunteering,
e-mail: youngathletespeoria@yahoo.com

Curt & Amanda Nauman

Memorial/Recognition Donations

The Heart of Illinois Down Syndrome Association, Inc. warmly accepts memorial donations of any amount. Since we are a volunteer organization, all dollars received go toward fulfilling our mission of improving the quality of life of persons with Down syndrome. The Heart of Illinois Down Syndrome

Association, Inc. is a 501(c)3 not-for-profit organization and all contributions are tax deductible.

Heart of Illinois Down Syndrome Association, Inc.

29th Annual
SPAGHETTI DINNER

Sunday, March 4, 2018 • 11:00 a.m. - 6:00 p.m.



\$8.00/Adult
(13 & up)

\$5.50/Child

Under 3 yrs.
FREE

ITOO Hall
4909 W. Farmington Rd., Peoria, IL

Raffle

Take out orders available

Entertainment

Bake Sale



FUN for the
entire family!

Dinner provided by LaGONDOLA SPAGHETTI HOUSE of Decatur

PLEASE HELP MAKE OUR 29TH SPAGHETTI DINNER FUNDRAISER A SUCCESS!!!

1. VOLUNTEER

Volunteers are needed to help set up, serve dinners, clear tables, and clean up. We are using SignUp.com (formerly VolunteerSpot) so people can choose the job they want in the 2-1/2 hour time slot they prefer. If you have any questions, contact Anne Hollis at (309) 219-5899.

To pick your job, the easiest way is to go to our facebook page at www.facebook.com/HOIDSa/ and find the post for volunteer sign up. If you receive our e-newsletter, click on the link below:

<https://signup.com/client/invitation2/secure/2190256/false#/invitation>

SET-UP FOR THE DINNER will be Saturday, March 3rd.
Contact Meri Tucker at 309-694-2984 if you can help out.

On the day of the dinner, volunteers are asked to park across the street at Midwest Implement or at least on the far end of the parking lot and leave the close spots for our guests.

2. DONATE ITEMS FOR THE RAFFLE & SILENT AUCTION

Raffle items are needed for the main raffle and kids raffle. We would also love for you to donate a basket for the silent auction, but we welcome single items and will create baskets for them. Please direct all donations through Amanda Nauman at (309) 360-1133 or anauman@mtco.com to prevent duplication.

We welcome your help soliciting items from businesses and small business owners. This is also a great way for them to advertise their products and make a contribution to a 501(C)(3) nonprofit organization. Tax-deductible receipts are available.

Contact Amanda Nauman or Christy Getz at (309)635-7309 or jcgetz94@yahoo.com for more information.

3. DONATE BAKE SALE ITEMS

Bake sale items will be accepted throughout the day. We will be happy to package and price the items for you. Please indicate what flavor the item is if it is not evident.

Gluten free items and goodies for diabetics are greatly appreciated.

If you cannot attend the dinner but wish to donate to the bake sale, you can arrange to have your items picked up. Please contact Teri Ehrenhardt at (309) 645-5690 to arrange for pick up.

4. HELP US ADVERTISE

Download fliers from our website and share with others. Fliers can be found at www.hoidsa.org. Post them at work or on Facebook. Tell everyone you know to come out & have a great meal for a good cause!

The meal includes ALL-YOU-CAN-EAT LaGondola spaghetti, salad, garlic bread, and a drink.

5. SELL RAFFLE AND DINNER TICKETS

Please sell raffle tickets and advance dinner tickets to your family, friends, and co-workers. Tickets are available from Milly Howeler (309) 692-3688.

6. MAKE A POSTER TO SHOW OFF YOUR KID

Don't forget to make a poster using a half-size poster board (either horizontal or vertical) with lots of pictures of your child and family for display! Please include your name and contact information on the back if you want your poster returned.





**HEART OF ILLINOIS
SPECIAL RECREATION
ASSOCIATION**



ACCESS the March Madness EXPERIENCE

Come enjoy a special day at the March Madness Experience at the Peoria Civic Center!

HISRA staff and hundreds of volunteers will adapt all of the games and activities in the March Madness Experience and make them accessible to people with disabilities!

Field Trip Day

Tuesday, March 13, 2018

9:30 am - 2:00 pm

Peoria Civic Center, Peoria, IL

All students with disabilities, group homes residents and members of Special Recreation Associations from around the state of Illinois are invited to join the HISRA staff and volunteers for a day of fun at the March Madness Experience. Doors will open at 9:30 am; come for a few hours or stay and enjoy all of the activities until 2:00 pm. Don't forget to bring sack lunches or money for the concession stand. There are accessible restrooms and a changing area will be set up for your convenience.

Family Night and Special Needs Information Fair

Tuesday, March 13, 2018

5:00 pm - 8:00 pm

Peoria Civic Center, Peoria, IL

***Stop by the
HOIDSA booth!***

Calling all families with children and adult with disabilities from around the state of Illinois! You are invited to join the HISRA staff and volunteers for an evening of fun at the March Madness Experience along with a variety of vendors and support providers who work with people with disabilities! The Special Needs Information Fair is sponsored by the Dunlap and Central Illinois Special Needs Parent Group. The March Madness Experience will be open for this special event from 5:00- 8:00 pm. The concession stand will be open, there are accessible restrooms and a changing area will be set up for your convenience.

Request your FREE TICKETS and FREE PARKING PASSES via e-mail : jwahl@peoriaparks.org

FREE
Workshop

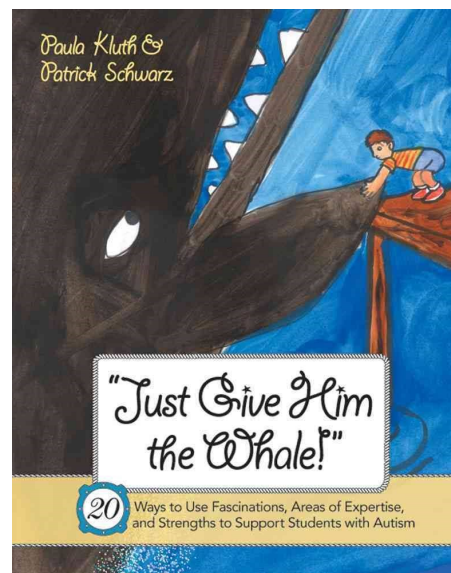


Presents
Patrick Schwarz
"Just Give Him the Whale"

Heartland Community College
1500 West Raab Road, Room 1406/1407
Normal IL

Tuesday, March 13, 2018
9:00 am—3:00 pm

Considering the fascinations, passions and interest areas of learners, powerful new ways of viewing these areas as positive teaching tools that calm, motivate, and improve learning will be illustrated. Using authentic student examples, participants will discover how to make the most of fascinations, passions, and interest areas to help learners they support. Areas included will be learning standards-based academic content; developing social connections; minimizing anxiety; boosting literacy learning and mathematics skills; expanding communication skills; and much more!



Register at <https://starnet.org/home/events/just-give-him-the-whale/>



Inclusion Town Hall

Join Early CHOICES and STARNET for an evening focused on the experiences of families who have children with disabilities, and how inclusion made a difference in their lives. We will hear from providers who support children too. We know inclusion has a foundation in the law, research has shown it is effective and federal guidelines support it; now we listen to the great things that happen for children with disabilities and their families when they are meaningfully included in their early childhood community.

Register for the Inclusion Town Hall:

March 12, 2018
Heartland Community College
6:30 pm – 8:00 pm

Early CHOICES is the Preschool LRE Initiative of the Illinois State Board of Education. We promote increasing high quality inclusive education for each and every preschool aged child.

Visit www.eclre.org to learn more.



Collaboration - Schools & Families Working Together

Saturday, March 3, 2018 10:00am to 12:00pm

Are you comfortable communicating with school staff? Do you want to be more effective in securing appropriate school services for your child without conflicts? At this FREE workshop participants will learn parent expectations, teacher expectations, conflict resolution techniques, and being unconditionally constructive.

Location: Child's Nature Pediatric Therapy Services
3002 N Main St
East Peoria, IL, 61611

Register at <http://www.fmptc.org/node/4066>

FREE
Workshop

Making Inclusion Work: Get on Board! (Webinar)

TUESDAY, MARCH 13, 2018
7:00 PM - 8:30 PM

Presenters: Emily Reilly and Emily Ropars

Making Inclusion Work: Get on Board is the first in a 3-part introductory series focusing on providing the basics of high quality inclusive programming. Join us in this free series as we use the Illinois model for "What Makes Inclusion Work in Early Childhood" to guide you through the research-based practices shown to improve successful implementation of inclusive programming. Part one will focus on the historical and current context related to inclusion, attitudes and beliefs, and program philosophies that support inclusion. It is not required to register for all webinars in this series, but is highly recommended.

Intended Audience: Administrators, ECSE Educators, General Educators, Teacher Assistants, Family Members, Family Educators, Psychologists, Social Workers, SLP's, OT/PT's

Register at <http://www.eclre.org/events/31318-making-inclusion-work-get-on-board-webinar.aspx>

Illinois Family Leaders Collaboration presents the 12th Annual Family Conference

Saturday, April 7th, 2018
Spalding Pastoral Center
419 NE Madison Ave, Peoria, Illinois

Registration: 8:30am to 9:00am

Conference: 9:00am to 3:00pm

Featuring The Shut Up Sisters, Gina Gallagher & Patricia Terrasi

Shut Up About Your Perfect Kid: A Survival Guide for Ordinary Parents of Special Children

On a perfection-preoccupied planet, sisters Gina Gallagher and Patricia Terrasi, dare to openly speak about the frustrations, stigmas, joys, and challenges they face as parents of children with disabilities (one with Asperger's syndrome, the other with bipolar disorder). This refreshingly frank and enjoyable presentation, based on their book, has participants laughing out loud and celebrating the joys, gifts, and milestones of special children. Participants will learn:

- How laughter can be a powerful coping techniques.
- How to deal with insensitive people.
- How to get your children the services and the support they need.
- How to help break stigma.
- How to see the joys and gifts in raising special children.

WHO SHOULD ATTEND

The Conference is for adult family members & caregivers of children (birth-22) who have developmental delays or disabilities. Service providers & educators are also welcome.

CONFERENCE COLLABORATORS

Early CHOICES • Family Matters Parent Training Information Center • Heart of Illinois Down Syndrome Association, Inc. • Project Reach: Illinois Deaf Blind Services • STARnet Region I & III • The Arc of Illinois Family to Family Health Information Center / Family Voices • Parents of individuals with disabilities

REGISTRATION

There is a **\$15 per person (nonrefundable) registration fee for family members** and a **\$25 (non-refundable) registration fee for professionals**. Breakfast and lunch are included. **Checks should be payable to "Family Matters," but mailed with the registration form to Starnet Regions I & III (address on form) by March 24, 2018.** Registration is limited. **CHILDREN CANNOT BE ACCOMMODATED AT THE CONFERENCE.**

The registration form can be downloaded and printed from

<https://www.illinoislifespan.org/events/illinois-family-leaders-collaboration-12th-annual-family-conference-featuring-the-shut-up-sisters-gina-gallagher-patricia-terrasi/>

HOIDSA members will be reimbursed for their registration fee by submitting a copy of their receipt to Milly Howeler, 5624 N. Graceland Dr., Peoria IL 61614.

STIPEND AND SCHOLARSHIP ASSISTANCE FOR FAMILIES TO ATTEND EDUCATIONAL CONFERENCES



What is a STARNET Fellowship?

To promote family education and professional development for individuals in Northwest and Central Illinois, STARNET Region I & III (part of a grant funded through the Illinois State Board of Education) offers fellowships. A fellowship is a monetary award that reimburses eligible family members (up to \$125 each) and early childhood professionals (up to \$100 each) for certain expenses associated with attendance at an Illinois training event. Individuals may apply for a maximum of two fellowships per grant year (from July 1st to the following June 30th). Awards are based on available funds and approved at the discretion of the STARNET staff.

Family Fellowships

STARNET provides fellowship reimbursement funds for family members to attend educational and informative events in the State of Illinois. If you live within StarNET Region I & III, are a family member of a child two through six years of age with an IFSP or an IEP, you are eligible. Funds may be used for workshop registration, travel expenses/mileage, lodging, or childcare costs. Fellowship awards are not, in anyway based on your income. Limited funds are available for individual requests of up to \$125 per award. Individuals may apply for no more than two fellowships in the grant year from July 1st to the following June 30th. Fellowships are limited to two per individual, not two per family.

Application forms must be submitted at least one month prior to the event for which you are seeking funding.

Awards are based on available STARNET funds and are approved at the discretion of the STARNET Staff. The STARNET grant is funded through the Illinois State Board of Education. If there are any questions about the process, please call (800) 227-7537 ext 251.

How do I Apply?

At least ONE MONTH before the event, mail or fax a fellowship application or fill out the online form:
<https://starnet.org/home/fellowships-2/fellowships-form/>

PRE-APPROVAL IS REQUIRED.

Please visit their website starnet.org for more information.



The Arc of Illinois, through a grant from the Illinois Council on Developmental Disabilities, administers the Consumer Involvement Program and distributes consumer stipend funds to enable people with developmental disabilities and their family members to attend conferences of their choice that are directly related to developmental disability issues.

What Can I Apply For?

Conference must be directly related to developmental disabilities at an in-state or out-of state conference

How much can I apply for?

- \$400 per person per year
- \$700 per family per year

Limitations: Participants are limited to a maximum of two stipends per year per individual or family within funding limit.

What Can I Use These Funds For?

- Conference Registration
- Child Care
- Respite Care
- Meals
- Personal Attendant
- Hotel
- Transportation

How Do I Apply?

The application form must be completed and returned to The Arc of Illinois with a copy of the conference brochure and a completed registration form at least 30 days prior to the date of the conference/workshop.

<https://www.thearcofil.org/consumer-stipend-funds-application-form/>

Please visit their website www.thearcofil.org for more information.

Adorable Lucas Warren made history last week by becoming the first “Gerber Baby” with Down Syndrome in the company’s 91-year history. The 18-month-old from Georgia was chosen from a pool of 140,000 babies who entered the contest, and his parents, Jason and Cortney Warren, say they were shocked by the news.

“It’s almost like a dream,” Cortney Warren, from Dalton, Georgia, tells PEOPLE. “I think it takes a minute to really set in, like, this *is* real.”

Since then, the couple has received thousands of messages on social media—they say they’re still getting used to all of the attention.

“It’s very humbling,” Jason Warren says. “Who knew our child was going to touch so many people and make that many people smile. We’re loving what everybody is saying about our little boy. Lucas is loving it—he’s loving all these new people he gets to wave at.”

Cortney says she entered Lucas into the contest on a whim at her son’s godmother’s urging. While Lucas is definitely soaking up his time in the spotlight, his parents say Lucas is not much different than any other toddler.

“He’s pretty much like every child around this age, loves learning, loves to laugh, loves to make other people laugh, always waving and smiling at everyone,” she says. “He loves it when complete strangers wave and smile back at him. It makes his day.” The winning photo of Lucas, which features him in a polka dot bowtie and green button-up shirt, was snapped after his first Sunday at church.

The complete story can be found at <http://people.com/human-interest/gerber-baby-parents-speak-out/>

HOIDSA RESOURCES

IEP Resource Advisors

For many of us IEP season is here! Do you have questions or concerns? Several HOIDSA moms who have experience with special education law and are knowledgeable about school issues and accommodations/modifications would like to act as resources for other parents in our group who have questions or concerns.

Feel free to contact:

Teri Ehrenhardt - 309-645-5690

ehrenhar@gmail.com

Deb Fornoff - 309-444-2508

debforoff@comcast.net

Julie Heim - 309-263-8293

ajheim@mtco.com

Christy Sanchez - 309-339-8823

christys0328@gmail.com

PUNS Process/Housing Options

At the Housing & Funding Options workshop on January 25th, Lisa Evans from CISA provided a detailed handout about the Prioritization of Urgency of Need for Services (PUNS) waitlist, including the enrollment process, how the PUNS selection works, and services that are available after an individual is selected. A handout was also distributed that includes a summary of service definitions, types of housing options for the developmentally disabled, and vocational programs for adults. Greg Cassidy from TCRC seemed very willing to “think outside the box” for creative housing and employment options for which his agency could provide assistance.

The handouts are located on the HOIDSA website <http://www.hoidsa.org/resources/puns-process-housing-options>



Everybody had a great time at the dance party on January 27th. We appreciate Julie Heim and her crew for organizing this event, supplying the snacks and goodies, and keeping the pizza coming! Many thanks to Judy and Dennis Triggs & Lori and Ken Harding for all their help at the Dance Party. As always a huge thank you to our DJ Chuck Tucker! He did a great job spinning the tunes and keeping the dance floor hopping.



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Hundreds of Parents of Kids with Down Syndrome Are Getting "The Lucky Few Tattoo"

Late last year, Mica May, a mum of three children, one of which has Down syndrome, was at a retreat surrounded by other mums of kids with Down syndrome when the idea to get matching tattoos started making its way through the group. Months later, what's resulted is a simple and clean three-arrow tattoo on the bodies of hundreds of parents, referred to as "the lucky few tattoo."



"The three arrows symbolize the three 21st chromosomes and how we rise up and move forward. We fly the highest after we have been pulled back and stretched, sometimes even more we think we can bear." There's no overestimating how much a sense of belonging can help people through hard times. The Lucky Few Tattoo is a constant, visual reminder for these parents of why the challenges are worth it.

#theluckyfewtattoo





c/o Bethel Lutheran Church
325 E Queenwood Rd Morton IL 61550

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Spaghetti Dinner
March 4th



EDITOR'S REMARKS

Hello Everyone!

One of HOIDSA's largest fund-raisers is right around the corner: the annual Spaghetti Dinner. Please take some time to review the information on pages 4 and 5. We need lots of help to make this Spaghetti Dinner another successful fundraising event.

There are some conferences coming up with great speakers. If you haven't seen Patrick Schwarz, register for his workshop! I also encourage you to attend the Family Leaders Annual Conference in April, which is free for HOIDSA members, or register for the StarNet webinar or Family Matters workshop in March if you need more confidence advocating for your child's education.

Carol Nepolello
c.nepolello@comcast.net

THINGS TO DO

Special Recreation Activities:
Check Out the Upcoming Activities
HISRA • IRVSRA • Pekin Park District

Contact HISRA at 309-691-1929

or visit hisra.org/programs/

Contact IRVSRA at 309-699-3923 or visit
www.fondulacpark.com/recreation-programs/

Contact IRVSRA-Pekin Park District
at 309-347-7275 or visit
www.pekinparkdistrict.org/irvsra/index.html