

# THE DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

November 2011

Affiliate of the National  
Down Syndrome Congress  
and the National Down  
Syndrome Society

A P U B L I C A T I O N O F T H E D O W N S Y N D R O M E G U I L D O F D A L L A S

## 2011 Buddy Walk®

**S**unday, November 13, 2011

Flag Pole Hill at  
White Rock Lake

8700 E. Northwest Highway  
Dallas, TX 75238

Activities begin at 11:00 am  
Walk begins at 1:00 pm

The 2011 Buddy Walk®, Dallas' biggest community awareness event in support of families of children with Down syndrome, is almost here. The Buddy Walk® is an incredible day of celebration with family and friends to raise awareness, raise funds, and raise hope of a better world for all people with Down syndrome.

We hope that you will join us for a fun filled day that includes a one mile awareness walk, bounce houses, obstacle courses, slides, music, games, food, and most of all friends and family.

### Buddy Walk® Challenge

The Buddy Walk® helps to raise funds to support the programs offered by the Down Syndrome Guild of Dallas, including educational seminars for families of school age children, parent to parent support, options for adults, and social events for all ages. Our goal this year is to double the donations and sponsorships we had last year, but we need your help.

There is still time to form a Buddy Walk® team and begin raising funds by following the simple online registration at [www.downsyndromedallas.org](http://www.downsyndromedallas.org).

Online registration makes it easy for teams to register and encourage giving. It also allows teams to reach out to friends and family outside the Dallas community with a simple e-mail link. Please contact the Down Syndrome Guild office at (214) 267-1374 or [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) if you need assistance with online registration and giving.

### Tips for Building your Team:

*Start with people that are closest to you:*

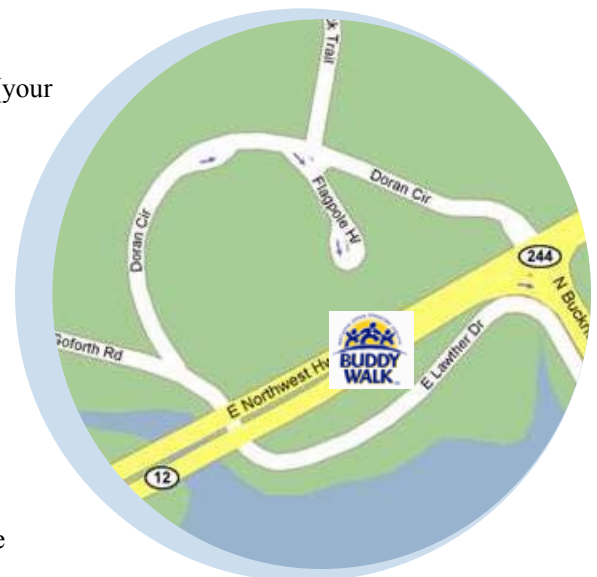
1. Family Members
2. Friends
3. Neighbors
4. Business Associates
5. Others in the community (your hairdresser, doctor, etc)

### T-Shirt Pick Up

Team captains will have the opportunity to pick up their team t-shirts at the DSG office prior to the Buddy Walk® by appointment only. Please contact the DSG office at (214) 267-1374 or [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) to reserve your time on one of the following days:

1. **Monday, October 31 - Friday, November 4 (10:00 am - 4:00 pm)**
2. **Wednesday, November 2 (10:00 am - 6:00 pm)**
3. **Saturday, November 5 (10:00 am - 2:00 pm)**
4. **Monday, November 7 - Thursday, November 10 (10:00 am - 4:00 pm)**
5. **Wednesday, November 9 (10:00 am - 6:00 pm)**

T-shirt orders previously reserved by team captains can be picked up at the event on November 13, from 10:00 am until 11:30 am ONLY. After 11:30 am, t-shirts will be released for distribution to donors who give at the event; therefore, we encourage all teams to take advantage of the dates and times listed above.



## GREAT WAY TO HONOR LOVED ONES

# Club 21

*is a Down Syndrome Guild program to honor a loved one: matching the numeral of the important chromosome that affects our children.*

A gift to the Down Syndrome Guild to honor loved ones is a tangible way to recognize their lives, celebrate holidays, birthdays, anniversaries, graduations, new homes, or any number of occasions.

A gift in honor of a friend or relative is a thoughtful and caring way to express sympathy while sharing concern for an important cause. Upon receiving a memorial or an honorarium gift, the DSG will notify the family or individual of your thoughtfulness and send you, the donor, a letter of receipt.

Interested in making a *Club 21* donation this holiday season? Contact Neely Holland by e-mail at [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net) or by phone at (214) 267-1374.

## From the Executive Director *by Neely Holland*

**"***If everyone is moving forward together, then success takes care of itself."* Henry Ford

We are well into the Fall, and that means we are half way through our event season! I am pleased to report that we had another successful **Herb's Paint & Body/Down Syndrome Guild Golf Classic** in September. We are so grateful to the team at Herb's Paint & Body for partnering with us each year and would like to recognize that the money raised from the tournament goes right back into programs, outreach, and information for our families. In October, we hosted our annual **Learning Together Focusing on Possibilities Fall Conference**. The attendees included educators from around the Metroplex, parents, social workers, and other professionals. The DSG Education Committee was pleased to offer an array of topics that covered all ages and different learning skills. And now to November and that means **Buddy Walk®!** We are so excited for this time of year, and we look forward

to having a record breaking fundraiser while increasing Down syndrome awareness. I encourage everyone to participate in some way. You can join a team, form a team, donate, or come the day of and walk! After a busy Fall, we finish the year with **Snackin' with Santa** in December! We are excited to bring the event back to its old location, so please take note of the article in this publication.

Every year we look forward to the Fall months and all of our wonderful events. However, it must be said that all of these wonderful activities are because of the people who back them. Thank you to the committees, the committee chairs, volunteers, and our membership for all that you do. Each of you plays a vital role in the success of these events, and it is because of that effort that they continue to grow every year. You, whether you helped plan and execute or participated and attended, have allowed our mission at the DSG to continue to thrive. I am truly grateful!

## 2012 Wall Calendars Now Available \$15 each plus \$2 shipping

**T**he annual Down Syndrome Guild calendar featuring the beautiful faces of our very own Guild members is now available. The DSG calendar makes a great holiday gift for friends, family, teachers, therapists, or colleagues. Proceeds of this year's calendar will support the programs and services offered by the DSG, but more importantly create awareness for

individuals with Down syndrome in the community.

The cost of this year's calendar is \$15 each plus \$2 shipping. Order online at [www.downsyndromedallas.org](http://www.downsyndromedallas.org) by clicking on the calendar icon. For questions or help with your order, please contact the DSG office at (214) 267-1374 or e-mail Jennifer Ford at [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net).

## Handwriting Helps *by Carla Austin, Occupational Therapist*

**H**andwriting is one of the major tasks facing the school age child. It is a realistic goal for most children with Down syndrome. This article and upcoming articles will explore the challenges faced by the young person with Down syndrome as they learn to write, the "compensations" frequently made by the individual as they spontaneously try to accomplish writing tasks, and methods to address these difficulties.

Low muscle tone throughout the arm and hand form a poor base for beginning writing. A flattened palm and lack of stability on the little finger side of the hand decreases the ability to shape the hand and free up the thumb side of the hand to skillfully hold and direct a writing instrument. Handwriting does not require a great deal of strength but does require much control. The child with Down syndrome frequently compensates for this lack of control when beginning to write by grasping the pencil in a fist and directing the pencil with movement of their whole arm. Frustration can rapidly interfere with completion of home and school work.

The following activities can help prepare the hand for beginning writing by building the arch in the palm and stability in the hand. These activities can also help the older child to have greater control and better endurance with writing tasks as well as increase general fine motor coordination for many manipulative tasks. Because these tasks require small objects, they should not be used with children who continue to mouth small objects.

1. Manipulate objects within one hand keeping the nondominant hand in their lap. Using the dominant hand,

place objects one at a time in their palm and encourage the child to move it into their fingers to place pennies in a bank, tiny pegs in a board, and beads onto a string held with the other hand.

2. Use small sugar tongs or children's chopsticks. The instrument should be held in an underhand rather than an overhand grip with the tool resting in the thumb web. Pick up cotton balls, marbles, or small beads and put them one by one into a container using tongs or eat a snack such as raisins using the tongs.

3. Practice pencil-walking down a pencil from the eraser end of the pencil held in the same underhand grip described above. The pencil should end up in the thumb web space resting in the C shape formed by a circled thumb and index finger. Pencil walking is a great turn taking activity for pencil games such as tic tac toe sharing one pencil between each opponent using pencil walking with every turn.

4. Use a cupped palm to scoop beans or rice. Practice finger spelling words using sign language letters such as c, d, e, and o, encouraging cupping of the palm. Squeeze putty, clay, or playdoh between the thumb and each finger. Practice thumb touching to the tip of each finger. Finger puppets or stickers can encourage young children to practice these movements.

5. Coloring within stencils, velvet coloring pictures, and coloring books outlined with Wikki Stix build control especially if an adult helper stabilizes the arm to encourage movement to be isolated in the wrist and hand. Scrapbook rub ons can help the older child practice the same movements in a more age appropriate way.

Give repeated practice and praise for a job well done!

## White Elephant Holiday Party for Adults with Down syndrome (Ages 19 and Older)

**S**unday, December 4, 2011  
1:00 pm - 3:00 pm  
3017 Sewanee Dr.  
Plano, TX 75075

(The home of DSG Program Specialist Cara Prentice)

Everyone loves a good holiday party! Self advocates ages 19 and older are invited to get dressed up in your best holiday sparkles and join us for a fun afternoon of food, music, and friendship. We will have a white elephant gift exchange, so **please bring a \$10.00, wrapped, unisex gift** so you can play the game. We also will be helping our local neighbors in need, so all guests are asked to **bring canned goods which will be donated to the North Texas Food Bank**. Due to space constraints, participants **MUST RSVP** to Jennifer Ford by phone at (214) 267-1374 or via e-mail at [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) **no later than Monday, November 29**. Happy holidays!

## From Your DSG Medical & Research Committee Roche Begins Early Stage Clinical Trial In Down Syndrome

**O**ur membership often requests information on research, clinical trials, and medical topics that may impact individuals with Down Syndrome and their families. As a result and in support of our organization's goal to "provide accurate and current information, resources, and support for people with Down syndrome, their families and the community," we are passing along this information to assist our families in educating themselves in these areas. The Down Syndrome Guild of Dallas believes by providing this information, each family will be able to make decisions based upon their personal beliefs and situation. The information presented does not necessarily express the views of the Down Syndrome Guild of Dallas and its distribution is intended to inform and not influence our readership.

The Down syndrome Research and Treatment Foundation (DSRTF) recently released news of the achievement of an important milestone in Down syndrome research. The pharmaceutical company Roche is going to enroll participants in clinical trials to test the safety and tolerability of a drug intended to address the cognitive and behavioral deficits associated with Down syndrome. The full text of Roche's press release is included below as well as on the DSRTF homepage at <http://www.dsrtf.org/>.

**First potential therapy designed to improve cognition and adaptive behavior in individuals with Down syndrome**

Roche (SIX: RO, ROG; OTCQX: RHHBY) announced the initiation of its first Phase 1 clinical trial to investigate the safety and tolerability of a molecule designed to address the cognitive and behavioral deficits associated with Down syndrome.

"There is currently a large unmet medical need for the treatment of cognitive impairments in individuals suffering from Down syndrome," comments Luca Santarelli, Global Head of Roche Neurosciences Disease Translational Area. "Our strategy at Roche neurosciences is to specifically address these serious conditions that have no approved, effective, or safe treatment. This is why we have a strong commitment to neurodevelopmental disorders, including genetic disorders like Down syndrome or Fragile X, as well as autism spectrum disorders."

Enhancing brain functions such as cognition and language in individuals with Down syndrome holds the promise to help these individuals conduct a more independent life. This may result from the improved ability to carry out every day's practical tasks such as finding an apartment, maintaining a job, or having a more fulfilling social life. These improvements can have a significant impact on functioning and quality of life of individuals with Down syndrome as well as help reduce the burden for families, caregivers, and the society.

"This study will target only adults between 18 and 30 years old, but we believe that an earlier intervention in Down syndrome has the potential

for a greater medical impact," says Paulo Fontoura, Head of Translational Medicine in the Roche Neurosciences Disease Translational Area. "While we are still at the early stage, we are confident that our drug's mechanism of action can potentially open the door to further promising investigations in upcoming years.

"Based on animal models, an imbalance between excitatory and inhibitory neurotransmission has been proposed among the underlying causes of altered brain function in individuals with Down syndrome. Roche's investigational drug is being assessed for its ability to address this imbalance by targeting the GABAergic\* system.

\*GABA: gamma-amino butyric acid

### About the study

This placebo-controlled study will assess the safety and tolerability of the investigational drug in individuals with Down syndrome. It will recruit up to 33 individuals in one or two countries. The investigational drug has already been tested in healthy volunteers and demonstrated a good safety and tolerability profile, without significant adverse events. For more information on the study, access the Roche Clinical Trials Protocol Registry and Results Database: <http://www.roche-trials.com/>

### About Down syndrome

Down syndrome is the most common genetic cause of intellectual disability and developmental delay, and affects one in every 700-1000 newborns. Also called Trisomy 21, this condition occurs when an individual has three, rather than two,

## What Are Our Housing Options? *Informational Meeting featuring Robin LeoGrande*

copies of the 21st chromosome. This additional genetic material causes some impairment of cognitive ability and physical growth and is often associated with other complications ranging from neurological and cardiac defects to hearing and vision problems. It is now thought that many people with Down syndrome are more likely to develop Alzheimer's disease as they age.

### About Roche

Headquartered in Basel, Switzerland, Roche is a leader in research-focused healthcare with combined strengths in pharmaceuticals and diagnostics. Roche is the world's largest biotech company with truly differentiated medicines in oncology, virology, inflammation, metabolism and CNS. Roche is also the world leader in in-vitro diagnostics, tissue-based cancer diagnostics, and a pioneer in diabetes management. Roche's personalized healthcare strategy aims at providing medicines and diagnostic tools that enable tangible improvements in the health, quality of life and survival of patients. In 2010, Roche had over 80,000 employees worldwide and invested over 9 billion Swiss francs in R&D. The Group posted sales of 47.5 billion Swiss francs. Genentech, United States, is a wholly owned member of the Roche Group. Roche has a majority stake in Chugai Pharmaceutical, Japan. For more information: [www.roche.com](http://www.roche.com).

**R**obin LeoGrande, President  
of Community for Permanent  
Supported Housing

Thursday, November 17, 2011

6:30 pm - 8:00 pm

Down Syndrome Guild of Dallas

1702 N. Collins Blvd. Suite 170

Richardson, TX 75080

Housing is an issue that touches every life, whether a person chooses to live independently, in a group setting, or remain at home with their parents. It's also an issue that can't wait until your child is ready to move to examine and explore. There are over 20,000 adults ages 20-62 with Intellectual and Developmental Disabilities (IDD) in North Texas. It is not hard to believe there are very few housing options for these adults. This is an important discussion for families of all ages of children and adults with Down syndrome.

Robin LeoGrande, President of Community for Permanent Supported Housing (CPSH) will discuss housing for adults with IDD in North Texas. CPSH creates collaborations among businesses, social organizations, and all levels of government to establish permanent, safe, cost effective housing options for adults with intellectual and developmental disabilities to enable these adults to pursue their best lives. CPSH also provides information regarding housing for adults with intellectual and developmental disabilities to the community.

Over the last 18 months CPSH has been researching the need for housing

in North Texas. This includes an online survey that collects information from families of children/adults with IDD. This is the only survey that is all inclusive of all types of IDD and is receiving attention across Texas. To complete the survey, go to the CPSH website at <http://www.txcps.org> and click the survey link on the front page.

Please complete the very short survey. In return you will receive the monthly newsletter about progress toward more housing options. On November 17, the survey results will be presented. Please RSVP to Jennifer Ford via e-mail at [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) or call the DSG office at (214) 267-1374.

## Snackin' with Santa

**S**aturday, December 3, 2011

10:00 am - 12:00 pm

Media Tech Institute

1130 West Trinity Mills Rd.

Carrollton, TX 75007

The Down Syndrome Guild's annual Snackin' with Santa is finally here. Parents have an opportunity to chat with friends, old and new, while children enjoy refreshments, games, prizes, crafts, and pictures with Santa. This holiday event is free of charge to all Down Syndrome Guild members.

This year, there will also be a game room/arcade with a pool table and ping pong for older kids.

Please contact Jennifer Ford by phone at (214) 267-1374 or via e-mail at [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) to RSVP or volunteer for this year's event.

## Teen Field Day Fun with YMSL (Ages 13-18)

**S**unday, November 20, 2011  
2:00 pm - 4:00 pm  
Prairie Creek Park  
(On the corner of Fall Creek and  
Prairie Creek west)  
Richardson, TX 75080

The Young Men's Service League (YMSL) is a non-profit organization that initiates and encourages young men and their mothers to pursue philanthropic involvement in their community and provides an opportunity to enhance mother/son relationships. The Dal-Rich chapter of YMSL will be hosting an afternoon out for DSG teens that are ages 13-18. The students will play rousing games of kickball and volleyball and also have snacks and some good old fashioned fun.

**Parents** - drop your kids off at the park and head over to Café Brazil for coffee and conversation with other parents. Café Brazil is located at 2071 N. Central Expressway, Richardson, Texas 75080-2706 (Southbound service road, next to AMF bowling).

To RSVP please contact Jennifer Ford via e-mail at [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) or call the DSG office at (214) 267-1374.

## Outstanding Educator of the Year Recipients

**T**he DSG is pleased to announce our Outstanding Educators of the Year. Awards were presented at our Fall Conference on October 22.

**Outstanding School of the Year – Creative Playday, a ministry of First United Methodist Church of Allen.** The school accepts preschool age students with special needs, providing integration into the preschool's curriculum. The staff is open and receptive to ideas and suggestions from parents, viewing parents as partners in the education of their child.

When a young child with Down syndrome was admitted to the preschool, a teacher took a sign language class in the summer before the school year began in order to be able to communicate with the child. The parent who nominated this school stated that every staff person at every level from the kitchen to the office to the classroom made her child feel welcome from the first day of school.

**Outstanding Educator Team of the Year – Melanie Beiling, Tamyé Roberson, & Amanda Mullens at Liberty Elementary School in Lewisville ISD.** The co-teach team believes that all students can be successful given the appropriate tools. The parent who nominated this team reported them to be an excellent model of inclusive co-taught education. Through team planning, modifying, accommodating, and communication with school staff and the parents, a 2nd grade student with Down syndrome progressed in the grade level curriculum and developed strong friendships.

**Outstanding Educator of the Year – Brittany Gullett at Castle Hills**

**Elementary School in Lewisville ISD.** Mrs. Gullett believes every child learns differently, and her job is to give them the right tools to maximize their success. She has high expectations for all her students. Prior to the 2010-2011 school year, Mrs. Gullett had never taught a child with Down syndrome. She attended sessions regarding the needs of the child who would be in her kindergarten classroom and continued spending her time throughout the school year reading and learning about how best to teach children with special needs, especially those with Down syndrome. The parent who nominated Mrs. Gullett says her child had an incredible successful year in the inclusive environment of the kindergarten class taught by Mrs. Gullett.

## Dad's Group Happy Hour

**W**ednesday, November 16, 2011  
6:30 pm - 8:30 pm  
The Londoner  
14930 Midway Road  
Addison, TX 75001  
(972) 458-2444

Join Down Syndrome Guild dads for drinks and conversation. Feel free to invite other dads who might enjoy attending.

RSVP to Neely Holland by phone at (214) 267-1374 or via e-mail at [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net). Not able to join this time, but would like to be added to the list to receive information for future events? Let us know that as well.

## Quarterly Meeting for Families of Babies with Down syndrome

**S**unday, November 20, 2011

3:00 pm – 5:00 pm

Location: Jewish Community Center of Dallas (JCC)

7900 Northaven Road

Dallas, TX 75230

Speaker: Debbie Clark

Topic: Talking with the Other Children in the Family

Parents are often concerned about what to say to the brothers and sisters of the new baby with Down syndrome. At what age will they be able to understand that their new sibling has Down syndrome? How much information is too much and how much information is not enough? What effect will the new baby's diagnosis

have on the other children? Come for a discussion about talking to brothers and sisters about Down syndrome.

Please join us to meet other parents, get information, ask questions, and find out how the DSG can be a resource and support for you and your family. We look forward to meeting you and your whole family.

Location: As you walk in the front door of the JCC, go straight down the main hallway to the first and second rooms on the right. The adults are in the Big D Room and the siblings have their own play room in the Yad B'Yad Room.

Please RSVP to Jennifer Ford by phone at (214) 267-1374 or via e-mail at [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net).

## White Elephant Holiday Party for Teens (Ages 13-18)

**S**aturday, December 3, 2011

3:00 pm - 5:00 pm

5913 Whittingdon

Plano, TX 75093

(The home of DSG parent Becky Igo)

Ring in the holidays with friends, food, and fun! Teens ages 13-18 are invited to join us for an afternoon of fun and a white elephant gift exchange. **Please bring a \$10.00, wrapped, unisex gift** so you can play the game.

This is the season of giving so we also will be helping our friends at Family Gateway Homeless Center. **All guests are asked to bring diapers, baby wipes, and/or bar soap and toiletries** to help local families get back on their feet.

Due to space constraints, participants **MUST RSVP** to Jennifer Ford at (214) 267-1374 or [dallasdsg@sbcglobal.net](mailto:dallasdsg@sbcglobal.net) **no later than Monday, November 29**. Happy holidays!

## Thank You to All Who Made the 5th Annual Herb's Paint & Body/DSG Golf Classic a Success

3M

Abuelo's

Allan & Jane Huston

Allen Samuels Dodge/  
Hyundai

Baker Drywall

Bank of America

Becky Igo

Ben E. Keith

Bin 303

Car-O-Liner Southwest  
Company

Castle Hills Mortgage

Collision Equipment  
Specialist

Corner Bakery

Dal-Chrome Company

Doug Bartol

Economy Signs

English Color & Supply

Enterprise

Family of Alana Drablos

Frost Insurance

Gold Metal Recyclers

Grand Bank

Hargrove Electric Co.

Joe Trahan/WFAA

L.A. Motocars

LKQ

M2Ventures

Mitchell International

Office Resource Group

Overall Parts Solutions

PARS Paintless Dent  
Repair

Red, Hot & Blue

Research Down  
syndrome

Rise School of Dallas

Ron's Towing

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Automotive Refinishes

Signature Towing

Silveron Capital

Stables Creative Group

Star Tire Co.

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Terri McKinney

The Hartford Retirement

Plans Groups

The Stewart

Organization

Toyota of Richardson

TRT Communications

United Market Street

Young Chevrolet

Zurich

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SUITE 170  
RICHARDSON, TX 75080

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(214) 267-1374

[www.downsyndromedallas.org](http://www.downsyndromedallas.org)

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DOWN SYNDROME GUILD OF DALLAS



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ARE YOU MOVING? DON'T FORGET TO PROVIDE US WITH YOUR CHANGE OF ADDRESS BY CALLING THE OFFICE OR BY E-MAIL AT [DALLASDSG@SBCGLOBAL.NET](mailto:DALLASDSG@SBCGLOBAL.NET).

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## Down Syndrome Guild Calendar of Events

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Informational Meeting

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