

# MOCA MESSENGER

VOLUME 11, NUMBER 2

MINNESOTA OVARIAN CANCER ALLIANCE

Summer 2011

## MOCA Float — Coming to a Parade Near You!

The Minnesota Ovarian Cancer Alliance has been the proud owner of a beautiful teal float for over a year and it just keeps getting better! Whether it is parked at the finish line to motivate runners to run for ovarian cancer awareness or towed in a parade providing candy and symptom cards to everyone it passes, the MOCA float is a wonderful asset to have and pretty incredible to see in action.

To kick off the float season of 2011, the MOCA float had the honor of encouraging several hundred runners as they headed to the start of the Spring Fling run in Rochester, Minn. on May 1. The float also marked the finish line so the runners could see the sparkling teal ahead and they knew the end was in sight!

Of course, none of this would have



**Runners line up at the Spring Fling in Rochester.**

been possible without the generous donor who gave MOCA a specific donation for the purchase of a parade float, complete with a parade banner and vehicle door magnets. The float is built on a trailer and self-contained in the sense that the sides fold up and it

has a weather-resistant cover to protect it during travel.

Come out and see the MOCA float in action! Upcoming dates are: June 18 in Farmington, July 3 in Nisswa/Brainerd, July 4 in Park Rapids, July 31 in Glenwood and at the Minnesota State Fair! Better yet, if you know of a parade or event that you would like to have the MOCA float present at, contact Jodi Bean at [jbean@mnovarian.org](mailto:jbean@mnovarian.org). You will need a valid driver's license, a vehicle capable of towing the float, and to coordinate the application process, pick-up and drop-off for the float. Past participants and members who have used the float tell us that once you use the float, you'll want to do it again! Contact MOCA at (612) 822-0500 or [PublicEd@mnovarian.org](mailto:PublicEd@mnovarian.org).

## MOCA Dream Awards



In 2010, we were excited to offer the MOCA Dream Awards for a second time and had the honor to present awards to 10 ovarian cancer survivors to fulfill their dreams. It all started in 2008, when an anonymous donor came to MOCA with an idea to support women with ovarian cancer. We introduced the MOCA Dream Awards, a program specific to supporting the dreams of women with ovarian cancer, and not one dream was the same. One woman was able to take her granddaughters to Disney World to experience truly being princesses while another woman was finally able to take her dream vacation with her husband to

Alaska. Others used the money for a special hobby or in pursuit of a personal passion to give back to others, and for many, it was for family vacations or gatherings.

We are thrilled to announce that this year the same generous donor has decided to once again fund MOCA Dream Awards for 2011!

MOCA Dream Awards are:

- To strengthen a woman's connection to her family or community
- To help her on healing journey
- For something that the woman might not be able to do, see or accomplish without the MOCA Dream Award

Six or more Dream Awards will be made to women with ovarian cancer who haven't previously received an award in amounts up to \$5,000 per award. MOCA Dream Awards are granted in November and then awarded at the annual MOCA Awards Night Meeting.

Applications for the MOCA Dream Awards will be accepted from June 10 until Sept. 19, 2011. The simple application is available online at [www.mnovarian.org](http://www.mnovarian.org) or you can call or visit the MOCA office for a paper copy.

Tell us about your dream and how MOCA can help make it happen!

## Letter from the President

Dear Friends,

I am hopeful the latest edition of the MOCA newsletter finds you enjoying the warm rays of summer in Minnesota. I know the staff and board at MOCA are looking forward to a glorious summer filled with fun activities dedicated to celebrating the women of MOCA.

I have just finished another year of school with a group of 24 first graders. Teaching is one of those jobs where the rewards are not found in the paycheck at the end of the month but in the smiles and hugs of six-year-olds and in the gratitude of the parents.

Each May, as the school year winds down, the children start thinking about the end of their relationship with you and they start to find ways to tell you how they feel.

One morning I walked over to my desk to find this letter.

*Dear Lisa,*

*Thank you for teaching us the entire school year. I loved every part of it having you as a teacher that you for all the things that you do*

*Love, Iris*

Now I hope you're laughing and thinking it's too bad I didn't teach her how to spell and finish sentences. And I should clarify that I have no idea why she addressed it to my first name.

This letter is not uncommon. The last few weeks I was greeted by many letters of love and kindness, from both my students and their parents. It made me grateful for the hard work and joy that we found together throughout the year. My last day was filled with love, hugs, tears and good-byes. I went home a tired but grateful teacher inspired by the lives that I touched.

So as I sat down to write this letter I

thought of all the people that we know in the ovarian cancer world that inspire us, care for us, teach us something, or work tirelessly for us. Many of them are similar to teachers, they work in jobs where the paycheck is not the reward at the end of the month but the reward is found in the lives that they have touched. What is different about their job is that they don't work with young children who wear their hearts on their sleeves.

I'm hoping that by reading this you will be inspired to write a quick note, email or card to someone who touches you. I'm thinking of it as my "pay it forward." I've been inspired by six-year-old Iris to wear my heart on my sleeve and thank someone for making a difference in my life. I hope you will, too.

*Warmly,*

*Lisa*

### Do you want to continue receiving the MOCA Messenger?

To make sure we are using our resources wisely, we are asking all members who would like to continue to receive the paper copy of the MOCA Messenger to "opt in".

You can do this by going to [www.mnovarian.org](http://www.mnovarian.org) and completing a short form. You may also email us at [MStGeorge@mnovarian.org](mailto:MStGeorge@mnovarian.org) with your name and address, or call 612-822-0500.

**If you do not contact us to let us know you would like to continue receiving the MOCA Messenger, you will be removed from this mailing.**

### Participate in Legislative Advocacy through Ovarian Cancer National Alliance

MOCA Board member Joy Wetzel and her husband John will be traveling to Washington, D.C. to attend the 14th annual conference of the Ovarian Cancer National Alliance, "Turning Promise Into Action," scheduled for July 9–12. The final day of the conference is "Advocacy Day." Advocacy Day participants receive thorough policy training on Monday afternoon, then meet with their senators and representatives on Tuesday morning to advocate for:

- Adequate and sustained funding for ovarian cancer research and awareness programs; and
- Legislation that improves quality of life and access to care for cancer patients.

If you're not able to travel to Washington D.C. for the conference, you can still participate by taking part

in Virtual Advocacy Day. Sign up at [www.ovariancancer.org/sign-up/](http://www.ovariancancer.org/sign-up/) to receive an email with instructions in how to take part in Virtual Advocacy Day. Together, we can ask our elected officials to maintain government funding and support for key ovarian cancer programs.

### Office Needs

- Large plastic containers
- Desktop Mac computer for design and video production
- Color printer — business grade

Please contact [cbarrette@mnovarian.org](mailto:cbarrette@mnovarian.org) prior to donating items.

## In Celebration of Life

### March 2011 to present

All of us at MOCA wish to honor and celebrate the lives of the following women who recently passed away. Their strength, courage and grace are to be admired. We will carry on the fight against ovarian cancer in their names. We extend our sympathies to their spouses, partners, children, family and friends.

Susan Carlson  
Cheryl Enos  
Dorene Karlson

Linda Scheid  
Betsy G. Slapnicher  
Dorothy Sonnek

## 2011 MOCA Calendar

July 17	<b>Mid Summer Night's Gala</b> , Lakeville
July 18	<b>Molly Cade Memorial Golf Tournament</b> , Lakeville
Aug. 2	<b>Survivorship Series — Understanding Palliative Care</b> , Minnetonka Community Center
Aug. 20	<b>3rd Annual Glenwood MOCA Open</b> , Glenwood, MN
Sept. 10	<b>12th Annual Silent No More Walk/Run</b> , Rosland Park, Edina
Sept. 27	<b>Survivorship Series — Rehabilitation After Cancer</b> , Brookview Community Center, Golden Valley
Oct. 20	<b>Survivorship Series — Clinical Trials</b> , Bloomington Center for the Arts
Nov. 12	<b>Diva Dash</b> , Centerville, MN

Check [www.mnovarian.org](http://www.mnovarian.org) for more details.

## Glenwood MOCA Open



**Saturday, August 20, 2011**

Curt and Amanda Ogdahl started the planning of the Glenwood MOCA Open in 2008 to honor Curt's mother, Marie. She battled ovarian cancer for eight years and sadly passed away on March 31, 2009.

"She was our inspiration for this tournament. Her attitude throughout her journey was remarkable. During her

chemo treatments she would always say that if it didn't help her, then hopefully they were able to help someone else. We weren't able to help Marie, but because of her we are hoping to help so many other women," said Curt.

Since the start of the first Glenwood MOCA Open in 2009, Curt and Amanda have been able to donate over \$12,000 to MOCA. This year's event will be held at Minnewaska Golf Course in Glenwood, Minn. and online registration is available at [www.mnovarian.org](http://www.mnovarian.org).



## Our Mission

- To create an awareness regarding early warning signs that may be indicative of ovarian cancer.
- To create and promote resources for support, networking and education for women diagnosed with ovarian cancer and their families.
- To unite and educate individuals, the medical community and organizations to achieve earlier diagnosis, better treatment and a cure for ovarian cancer.
- To advance ovarian cancer research toward earlier diagnosis, better treatment, and a cure.

## MOCA Board of Directors and Staff

Visit [www.mnovarian.org](http://www.mnovarian.org) to view:

- Board of Directors
- Medical Advisory Committee Members
- MOCA Staff
- Volunteers

**For more information or to contact MOCA's staff call (612) 822-0500**

*The information contained in this newsletter mailing or any enclosure contained herein, should NOT be considered a substitute for the opinion of a qualified health care provider. MOCA does not recommend or guarantee any product mentioned in this newsletter mailing or any enclosure contained herein. Please use this information to assist you in obtaining further information and in making your own health care decisions.*

# Silent No More Walk/Run is September 10th



Join us on Saturday, Sept. 10, 2011 for the 12th Annual Silent No More Walk/Run for Ovarian Cancer at Rosland Park in Edina. This year's event will be once again be hosted by KARE11 Anchor Rena Sarigianopoulos! Gather your family, friends and colleagues and invite them to join you at this year's event for the 5K Race, 2K Walk and the Kids Fun Run. Each year we welcome nearly 3,000 participants where we honor the women of MOCA. Individual participant, Family & Corporate Team registration and fundraising are now available at [www.mnovarian.org](http://www.mnovarian.org)!

We are still looking for sponsors and donations of items for the Survivor Goody Bags. Please email Courtney at [cbarrette@mnovarian.org](mailto:cbarrette@mnovarian.org) for more info!

## Special Prizes For Top Fundraisers!

Winners will be announced at the Awards Night Meeting

**1st level of \$250-\$499:** 5 credits to the MOCA store

**2nd level of \$500-\$1,499:** 10 credits to the MOCA store

**3rd level of \$1,500-\$2,499:** 20 credits to the MOCA store

**4th level of \$2,500-\$4,999:** 30 credits to the MOCA store

**5th level of \$5,000+:** MOCA Crystal Star Paperweight & 50 credits to the MOCA store

**The MOCA store credit can be applied toward any in stock items and can be redeemed after 11/01/11**

**Based on donations received by MOCA by September 30, 2010.**

Prizes are not cumulative and will be available at the Awards Night Meeting and MOCA Office after November 1

## Generous Donors Make MOCA's New Website Possible



As many of you may have discovered, MOCA has updated its website. Thanks to the generosity of Clear Software for Good, Jon Hanke, Greg

Carlson, Sarah Noonan, Michael Barnholdt and numerous others who have spent many hours on this project and continue to support the ongoing development of the site.

The new site features easy navigation and is packed full of information about ovarian cancer, support services, research news and updates, MOCA happenings and how to get involved.

We hope you take a moment to look through the site, we would love your feedback!

## Corn Dogs! Cheese Curds! Ovarian Cancer Awareness!

MOCA will have a booth at the MN State Fair this year from Aug. 25 to Sept. 5.

We will need volunteers for set up, staffing the booth, and tear down. Please check your calendar for when you'd like to volunteer and stay tuned!

The volunteer request will be coming out in late June with more specifics on blocks of time, days, and the parade! Email Jodi at [jbean@mnovarian.org](mailto:jbean@mnovarian.org) if interested.

**Donating to MOCA has never been easier!**  
Please check out our donation pages online at [www.mnovarian.org](http://www.mnovarian.org)

## Many Connected to MOCA at Annual Meeting

On May 10, 2011, the Minnesota Ovarian Cancer Alliance hosted its Annual Meeting, which is open to all members and the public to recap activities, expenditures, funds raised and to show volunteer appreciation. Almost 90 people attended the meeting in the Southdale Library in Edina, MN, braving traffic, heat and risky weather to hear what has been accomplished and the current happenings at MOCA.

The Annual Meeting is an inspiring evening spent with good food, great cake and wonderful people all dedicated to the importance of ovarian cancer awareness, support, treatment and, someday, a cure. MOCA looks forward to having members and supporters come from all over Minnesota to connect at the Annual Meeting.

The Annual Meeting includes short presentations from the next ovarian cancer

research awardees, which is great because researchers provide a quick overview of their projects and what they hope to learn about ovarian cancer. Also, this meeting provides an opportunity for discussions on what comes next, updates from the Board of Directors and feedback from the members.

Every year the Annual Meeting is held in the month of May, so if you didn't make it to 2011, plan on it for 2012! We look forward to seeing you next year.

### Research Awardees

#### Sanjeev Kumar MBBS

Department of Gynecologic Surgery, Mayo Clinic

Research title: *Ritonavir Repositioning from HIV-AIDS to Treatment of Ovarian Cancer*

Amount funded: \$55,480

#### Melissa A. Geller, M.D.

Assistant Professor, Department of OB/GYN and Women's Health, U of M  
Research title: *Lymphodepleting Chemotherapy and T-Cell Suppression Followed by Allogeneic Natural Killer Cells and Interleukin-2 in Patients with Recurrent Ovarian Cancer*

Amount funded: \$88,992

#### Viji Shridhar, Ph.D.

Professor, Department of Experimental Pathology, Mayo Clinic

Research title: *Targeting the Tumor Microenvironment in Ovarian Cancer*

Amount funded: \$68,746

#### Amy Skubitz, Ph.D.

Professor, Department of Lab Medicine and Pathology, U of M

Research title: *Novel Bispecific Ligand-Directed Toxins for the Treatment of Ovarian Cancer*

Amount funded: \$90,000

## Support and Information Available to You

### Support Groups

**Minneapolis** — Meets on the second and fourth Wednesday of the month from 6:00–7:30 p.m. at MOCA.

**St. Paul** — Meets the third Saturday of the month from 2–3:30 p.m. in the Old Main Building, room #003 at Macalester College.

**Young Survivor Network** — Meets on the third Tuesday of the month from 6:30–8 p.m. at MOCA. \*Two special Summer dates added: Thursday, June 30 and July 28.

**Brainerd Area** — Meets on the second Thursday of the month from 6–7:30 p.m. at the Nisswa American Legion, 25807 Main St., Nisswa, MN. This support group is open to survivors and support people.

**Southeastern Minnesota/Rochester** — Meets as needed. Contact the MOCA office for more information.

**Information Session for Women Newly Diagnosed with Ovarian**

**Cancer** — This is a one-time session for women who have been diagnosed in the past year. Next session: Aug. 17, 2011 from 6:30–8 p.m. at MOCA. RSVPs requested.

**R.I.S.E. Ongoing Support Group for Newly Diagnosed Women** — Quarterly support group for women within the first year of diagnosis. Next meeting: September 21, 2011 from 6:30–8 p.m. at MOCA. RSVPs requested.

**FORCE Support Group** — This group is open to anyone with hereditary ovarian or breast cancer in their family and those with BRCA 1/2. The group meets to provide support, education, awareness about hereditary ovarian and breast cancer and the BRCA mutation gene. Primary facilitator: Gwen Duckworth. For meeting dates, contact MOCA.

All support groups are free and subject to change. For more information or to RSVP, call (612) 822-0500, visit our website: [www.mnovarian.org](http://www.mnovarian.org) or email Jodi at [PublicEd@mnovarian.org](mailto:PublicEd@mnovarian.org).

### Other Support, Education and Meetings

**MOCA Mentor Program** — One-on-one support from survivors, partners of survivors, daughters who have lost their mothers to ovarian cancer, and friends of survivors. You will receive a phone call within three business days of your request, but usually sooner. To request a mentor, call MOCA at (612) 822-0500.

**Upcoming Survivorship Series Meetings** — MOCA hosts meetings for ovarian cancer survivors, family members and friends on topics addressing life with and beyond ovarian cancer diagnosis and treatment. Free and open to the public. Coming up:

**Ovarian Cancer Research Open House** on June 23 from 7–8 p.m. at Roseville Skating Center in the Fireside Room.

**Understanding Palliative Care** on Aug. 2 from 7–8 p.m. at Minnetonka Community Center.

## Public Education and the 2011 Survivorship Series



**M**OCA welcomed a new Public Education Program Manager, Jodi Bean, in mid-April. Jodi jumped

right into work on the Annual Meeting, Support Groups, planning for the MN State Fair and the Survivorship Series. Jodi comes to MOCA with experience in program management, public relations and a personal family connection to ovarian cancer.

MOCA's new Survivorship Series launched in 2011 with topics selected from feedback provided by MOCA members who shared what information they would like to hear. As we start planning for 2012, if you have a suggestion for a topic, contact Jodi.

On April 7, the first Survivorship Series meeting took place on "Living Beyond Cancer," presented by Brenda Hartman, MSW, LICSW. Her presentation moved many people in attendance and left the group with a lovely closing message about the bittersweet gift.

The second of the Survivorship Series meetings took place in May. The topic was "Spiritual Survivorship and Spiritual Distress," presented by

Chaplain Mary E. Johnson. Her presentation sparked genuine sharing and heartfelt discussions amongst the group of attendees.

Four meetings remain for the Survivorship Series in 2011:

### **Ovarian Cancer Research Open House, MOCA Research Grant Recipients**

Join us for an open house where recipients of MOCA research grants will display their MOCA-funded projects and answer questions about their efforts in ovarian cancer research.

Thurs., June 23, 7–8 p.m.  
Roseville Skating Center, Fireside Room  
2661 Civic Center Dr.  
Roseville, MN 55113

### **Understanding Palliative Care**

Kathy Bassett, Allina Palliative Care Program and Linda Linder, RN, Ovarian Cancer Survivor

Palliative care treats pain as well as addresses your physical, emotional and spiritual concerns after a cancer diagnosis.

Tues., Aug. 2, 7–8 p.m.  
Minnetonka Community Center  
14600 Minnetonka Blvd.  
Minnetonka, MN 55345

### **Rehabilitation After Cancer**

Andrea Cheville, MD, Associate Professor of Physical Medicine and Rehabilitation, Mayo Clinic Cancer Center

Ovarian cancer treatment can be a difficult road which may leave some women with side-effects such as lymphedema, pain management and other issues.

Tues., Sept. 27, 7–8 p.m.  
Brookview Community Center  
200 Brookview Pkwy.  
Golden Valley, MN 55426

### **Clinical Trials**

Hear from leading experts in cancer research about the importance of ovarian cancer clinical trials and why you might benefit by participating.

Thurs., Oct. 20, 7–8 p.m.  
Bloomington Center for the Arts,  
Rehearsal Hall  
1800 W. Old Shakopee Rd.  
Bloomington, MN 55431

Survivorship Series meeting registration is on the MOCA website. You can also RSVP by calling MOCA at 612-822-0500 or email Jodi at [jbean@mnovarian.org](mailto:jbean@mnovarian.org).

## MOCA's Young Survivor Network

**A**s MOCA's Young Survivor Network (YSN) continues to grow, we continue to seek new ways to offer information, support, hope and healing to survivors.

We define "young" as survivors who are dealing with unique issues based on age or phase in life. These include loss of fertility, forced menopause, raising children, dating after diagnosis and sexuality/body image issues. Most members range in age from mid-20's to mid-40's; however there is no age criteria to join.

We are excited to announce that we have recently opened our group to young survivors of any gynecologic cancer, including cervical, uterine/endometrial, and fallopian tube. We have discovered that we experience many of the same issues and we can therefore share our journeys and support each other through the healing process.

This summer, MOCA is piloting a second YSN meeting on the last Thursday of the month from 6:30–8:00 at the MOCA office. Specific dates are May 26, June 30 and July 28. We also con-

tinue to hold monthly meetings on the third Tuesday of the month throughout the year.

The YSN is putting together a basket for the silent auction at MOCA's Midsummer Night's Gala on July 17. Our theme is CHOCOLATE! If you are interested in donating, please contact us at [moca-ysn@chaska.net](mailto:moca-ysn@chaska.net).

For more information about MOCA's Young Survivor Network, please visit [mnovarian.org/offering-support/support-groups/moca-young-survivor-network/](http://mnovarian.org/offering-support/support-groups/moca-young-survivor-network/)

## Volunteer Spotlight

# Peggy Jennings



**P**eggy Jennings became a member of MOCA in 2003, when she was first diagnosed with primary peritoneal cancer. At the Walk/Run that

year, Peggy and her husband, Joe, met survivors who reached out to them with grace and warmth. The mentoring that followed led to Peggy's involvement with MOCA. She began by becoming a presenter in Survivor's Training Medical Students and by doing mentoring phone calls and visits to women newly diagnosed, activities she continues today.

After her cancer recurred in 2005,

Peggy decided to deepen her commitment to women with ovarian or primary peritoneal cancers. For the past five years she has been one of the lay reviewers of proposals to the MOCA Ovarian Research Grant Program and also serves as a research advocate on the Mayo Ovarian SPORE Patient Advisory Committee.

In 2010, she was one of 20 survivors nationwide invited by Livestrong to participate in the Biannual Survivorship Conference in Washington, D.C., representing MOCA. This conference, attended by over 550 people, focused on the need for each patient to develop a personal care plan before completing treatment. Peggy participated in discussion groups on everything from home nursing support

to fitness and nutrition coaching, as well as psychological, social and wellness care. "I was pleased to learn at this conference that, according to the National Coalition for Cancer Survivorship, the official definition of 'cancer survivor' now includes one's family, friends and caregivers," she said. "That is something Joe and I have known to be true for a long time."

Last year, Peggy and Joe volunteered at MOCA's first State Fair booth. "This was a fun experience; however, meeting many people with misconceptions about ovarian cancer reinforces my resolve to help raise awareness of what ovarian cancer is and how we can increase survivorship. In this life, we cannot always pay favors back, but usually we can find a way to 'pay it forward'."

## Medical Education Programs Update

# Survivors Teaching Medical Students

**T**his spring, MOCA members have been invited to speak to medical students at the Mayo Clinic in Rochester about their personal experiences with ovarian cancer, highlighting their cancer risks, symptoms and treatments.

Megan Chang, a MOCA member and a Mayo Clinic third-year medical student, and the Mayo Clinic's Family Medicine Interest Group invited a panel of three ovarian cancer survivors to speak to them at the Mayo Clinic on April 11. The three speakers — Ruth Gaylord, Carmen Williams, and Joy Wetzel — were very well received and the approximately 20 medical students who attended had a number of questions for all three speakers.

Dr. Jani Jensen, a member of the Mayo Clinic's Department of Obstetrics and Gynecology teaches a pre-clinical curriculum class on broad areas of OB/GYN subjects, including cancer, to medical students who are transition-

ing from their second to their third year of medical studies and from the classroom to the clinic. Dr. Jensen invited MOCA members Kris Greer, Sarah Noonan, and Carmen Williams to speak to approximately 50 Mayo Clinic medical students on June 8 about their ovarian cancer experiences as part of their studies of gynecologic malignancies. Students listened to their personal stories and asked questions.

Approximately 20 trained MOCA volunteers participate in the Survivors Teaching Medical Students program and provide information about ovarian cancer by invitation to medical students at the University of Minnesota Medical School and the Mayo Clinic in Rochester. For more information about the program, contact Kathy McGovern, Medical Education Programs Manager at [kmcgovern@mnovarian.org](mailto:kmcgovern@mnovarian.org).



## FORCE Support Group

**T**he FORCE Support Group is a monthly group open to anyone with an increased risk of hereditary ovarian or breast cancer and/or those who are considering testing or have tested positive with BRCA 1 or 2 gene mutation. The FORCE support group meets to provide support, education and awareness about hereditary ovarian and breast cancer and the BRCA gene mutation. The group is a safe place to discuss options and share experiences with personal choices amongst people who are in a similar situation. The primary facilitator, Gwen Duckworth, is very passionate about FORCE and looks forward to meeting you.

For meeting dates, contact MOCA at 612-822-0500 or email [PublicEd@mnovarian.org](mailto:PublicEd@mnovarian.org)



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*Celebrating*  
THE WOMEN OF MOCA

MOLLY CADE  
MEMORIAL  
GOLF  
TOURNAMENT



*Mid Summer  
Night's  
Gala*

July 17th & 18th  
Registration now open!