first
Foundation for Ichthyosis & Related Skin Types

Ichthyosis Focus

FALL 2021 • Volume 40, No. 2

A Journal for Friends of FIRST

WORDS MATTER

Much to Look Forward To


Mark Evans


Tracie Pretak

We hope you had a great summer. We are looking forward to the beautiful fall season, and then to the National Conference in June 2022! We know how much this event means to our members because of the opportunity to connect, re-connect, provide and receive support, obtain helpful information and meet with doctors who have experience treating patients with ichthyosis. We know our own families have greatly enjoyed past conferences and we are looking forward to safely meeting face-to-face once again! We also have three smaller in-person Patient Support Forums scheduled this fall in Seattle (September), Milwaukee (October), and Rehoboth Beach, Del., (November).

Our dedicated FIRST staff, working in collaboration with our volunteer Board of Directors, has developed a three-year strategic plan that spans advocacy, programs and services, research, development, and operational efficiency. One exciting success of this plan is that FIRST conducted an FDA Listening Session with the Food and Drug Administration in September. This was a key opportunity to raise awareness about ichthyosis, hear members share their stories of living with it, and increase interest in treatments and medical research. Thank you to all who collaborated to share your stories and medical expertise, and thank you to our staff for your organization and execution.

On the research front, we received a robust volume of research grant requests that are being evaluated by a committee of experts. Regarding fundraising, grassroots events have always been important to us. If you are interested in hosting one, please reach out to our FIRST staff. We continue to hold a wide variety of virtual events that offer the opportunity for you to learn and connect digitally.

FIRST is well-positioned for the future with a strong financial position, dedicated staff members, our MSAB (Medical and Scientific Advisory Board) and our volunteer Board of Directors, who all collaborate to accomplish FIRST's mission to improve lives and seek cures for those affected by ichthyosis and related skin types.

We look forward to the opportunity to meet you face-to-face, in a safe environment, to connect, re-connect and support each other.

Tracie Pretak

Mark Evans & Tracie Pretak
Co-Chairs, FIRST Board of Directors

FIRST HAS A NEW ADDRESS!

Foundation for Ichthyosis & Related Skin Types, Inc. (FIRST)
PO Box 1067
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FIRST exists to improve lives and seek cures for those affected with ichthyosis or a related skin type.

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first
Foundation for Ichthyosis & Related Skin Types

Beiersdorf Partnership Supports New Programs

FIRST is proud to partner with Beiersdorf, the makers of Aquaphor and Eucerin, on a series of programs to benefit individuals living with ichthyosis.

Beiersdorf US has a 20-year history of supporting those affected by ichthyosis and similar skin conditions by providing complimentary Aquaphor and Eucerin products through its medical donation program. To date, the program has helped more than 350 families.

Beiersdorf's Social Mission Project and Community Outreach Program is designed to lift up teenagers and young adults with ichthyosis. This summer, FIRST hosted a series of virtual sessions for these members focused on mentorship, building confidence, mental health and skin care.

We look forward to continuing this partnership and supporting our teen and young adult members in new ways!

CARE BEYOND SKIN
THE PURPOSE OF BEIERSDORF

Eucerin® Aquaphor

Patient Support Forums Resume This Fall

FIRST is excited to help bring members together by resuming Patient Support Forums this fall. These one-day meetings include medical discussion, research updates, and sharing among families. It's a great opportunity for members new and old to connect and support each other.

Patient Support Forums were scheduled to be held in Seattle on Sept. 25, in Milwaukee on Oct. 2 and in Rehoboth Beach, Del., on Nov. 13.

Virtual Events Continue

We continue to offer many ways for members to connect outside of in-person meetings. Here's a sample of what's to come:

- New Member Orientation: Oct. 12, Nov. 9, Dec. 14
- Ichthyosis and College: Oct.19

Learn more Our upcoming events are listed at firstskinfoundation.org/events.

Members Innovate to Raise Funds During Pandemic

COVID-19 has challenged FIRST's longtime grassroots donors to think creatively.

Congratulations to the Cina family of West Caldwell, NJ on their 11th wine tasting event, which raised $7,000! Parents Sean and Jolie have held the event to raise funds and awareness for their children, Portia (14) and Myles (10) who are affected with ichthyosis En confetti. Jolie, who is also a Board member, said "COVID-19 forced us to cancel last year and people were sad to miss it! This year, people from across the country sent in donations. The event was indoor/outdoor to make our guests comfortable. Portia performed three original songs. It was so great to see everyone again!"

Congratulations also to the Release the Butterfly production! This huge team, led by Board Co-President Tracie Pretak, has hosted over 21 productions in 6 years. In this time of limited in-person events they pivoted to hold 3 virtual events which have raised more than $9,600! Tracie and her daughter Bailey Pretak, who is also a Board member, have hosted other entertainment events during Covid, which raised an additional $3,560!

THANK YOU to all our grassroots fundraisers!

Tips for Creative Fundraising:

- Remember people are eager to connect
- Everyone has different boundaries – allow for many choices in participation
- Food, entertainment, and information are universal draws
- Use technology to get the word out and tell your story
- Contact FIRST to build a fundraising page

The Cina family (clockwise from left):
Sean, Jolie, Portia and Miles

Portia Cina performs for guests
at her family's wine tasting event

Driving Awareness with Car Show

By Abby Evans

This summer, multiple FIRST families gathered to check out some rides in Kansas City as part of a car show that doubled as a collaborative fundraiser. Friends, family and community members gathered to rally for awareness and community support.

The idea gained momentum when Johnny Ray Burt and Sarah Brosnahan, parents to 4-year-old Ryker Burt, reached out to two other families in the area -- Martha Randall and Calvin Keith, parents to Westyn Randall, and Stephanie Hawkins Garrett and Ronald Garrett, parents to Wyatt Garrett -- to plan an event to bring them together and raise awareness. Knowing that there are many car enthusiasts in the area, the families chose to organize a car show, but their main focus of the fundraiser was the social and emotional support they received from their community. Their fundraiser was a great way to support FIRST, but served as an even better way to educate, inspire, and connect with their community.

The car show was the first event of its kind, and FIRST recently became equipped with new tools that make fundraising, especially events like these, much easier for you. If you are hoping to host a fundraiser, FIRST can help you build an exciting, clever and easy way to get information out to your networks. These new tools offer options for lots of different events, including ways that fundraising teams can compete against each other to raise the most money.

For more information on hosting fundraisers, please contact Denise Gass, advancement director, at dgass@firstskinfoundation.org.

Ryker Burt sits behind the wheel of one of the cars at a fundraiser hosted by his family

GIVING
TUESDAY

Last year on Giving Tuesday, 34.8 million people gave to various nonprofits. Giving Tuesday is an opportunity for communities to influence each other and ask their friends and families to give to nonprofits they support. This Giving Tuesday, November 30, ask your friends to join you in giving to FIRST.

Aiming to Raise Funds

Thank you to William Bowman of North Babylon, NY who hosted an archery shoot fundraiser to benefit FIRST! The event featured a friendly archery competition with the Strong Island Bowhunting and Long Island Babes and Bucks groups, along with a raffle and refreshments.

The event raised $550 for FIRST!

Members of Strong Island Bowhunting and Long Island Babes and Bucks participated in a fundraiser for FIRST.

Writing for a Cause: New Books Aim to Inspire Confidence and Acceptance

by Bailey Pretak

Words. Words have the ability to make a person laugh or to fall in love. Words can hurt or heal. They can take someone to another time or another place. Words can make someone feel like they are seen or can cause someone to see things differently. Two people in our community have chosen to take the power of their words to inspire children around the world.

> **“I heard from many children with ichthyosis that they don’t often identify with characters in books or movies”**
>
> ***– Andrea Rustad, MD***

Andrea Rustad from Minnesota grew up with a skin condition, atopic dermatitis, and as a result became interested in dermatology. She first learned about ichthyosis when she volunteered as a camp counselor at Camp Discovery. While there, she heard heartbreaking stories from children about the social and bullying challenges that they faced regularly. This led her to pursue ichthyosis research as a medical student with her mentor, Dr. Amy Paller, at Northwestern University in Chicago. She discovered from the families she interviewed that these challenges often stem from the general public’s lack of knowledge on skin conditions.

Andrea Rustad has authored a children’s book about a girl with ichthyosis. Andrea is a third year medical student at Northwestern.

Jolien van der Geugten has published a children’s book in Dutch. An English version is expected later this year.

Rustad thought a book about ichthyosis could help address this. It could help explain ichthyosis on a level that would make sense to children and could be read to the classmates of kids with ichthyosis. “I heard from many children with ichthyosis that they don’t often identify with characters in books or movies,” she said. “I wanted to provide more representation for these children with this book, so that they can read it and identify with the characters and know that they are not alone. Recognizing the complexities, uniqueness and strengths of individuals helps us understand one another for every aspect that makes us who we are.”

The forthcoming book will be called “Skinvincible”. It follows a young girl with ichthyosis through a day in her life as she prepares to perform in a talent show. Along the way, it describes what ichthyosis is and how this affects parts of her daily life. It touches on bullying and how to stand up for yourself, as well as being a good friend.

Rustad’s hope with the book is that “those who have ichthyosis, and their families, feel represented…that this book educates others about ichthyosis, make kids with it feel less alone, and decreases bullying.” She said she wants to be a voice for these kids and is honored to be telling their stories. There is no set date yet for publication, as illustrations need to be completed, but FIRST will notify members once the book is available.

> **“Lucas was born with X-linked ichthyosis and when he started school, she searched for a storybook to explain to his classmates a bit more about his skin condition, but could not find anything.”**

Four thousand miles away, Jolien van der Geugten from the Netherlands is making her own splash with her children’s book “Luke & the Tiger”. She said her 6-year-old son, Lucas, was the inspiration for writing it.

Lucas was born with X-linked ichthyosis and when he started school, she searched for a storybook to explain to his classmates a bit more about his skin condition, but could not find anything. “This book gives me the feeling that I can do something for him,” van der Geugten said. It is vital that “children learn about differences between people at an early age, so that there is less prejudice and misunderstanding due to ignorance.”

In the story, Luke is the brave hero. He serves as a role model for children with ichthyosis, as they recognize themselves in the story and realize they are not alone. “Luke & the Tiger” is available now in Dutch and will be printed in English at the beginning of November. Go to lukeandthetiger.com to pre-order your copy.

More Writings About Ichthyosis

Andrea and Jolien are not the only two who have graced the world with stories of ichthyosis.

Check out some other authors from within our community:

Courtney Westlake, *A Different Beautiful*

FIRST member, Courtney Westlake explores what it was like for her family to raise a child with Harlequin ichthyosis. Throughout the book, she shares what they discovered about true beauty and teaches through her personal experiences how we can “celebrate God’s version of beautiful in our lives, especially within our differences and struggles.”

Anne Kaier, *Finding Refuge With the Skin I’m In*

Shared in a recent FIRST newsletter, Anne Kaier wrote an article for the disability column of The New York Times. In it, she shares the “delicate balance of talking about her ichthyosis without it sounding frightening or scary and without sugar-coating the struggles.” Her words help those unaffected to better understand our daily struggles and remind the affected that sometimes it’s okay to not be okay when we face our daily challenges.

Aliya Shahnaz Kraybill, *The Unexpected Benefits of Social Distancing*

If you missed hearing about one of our younger FIRST members, be sure to check out Aliya’s article written for a contest with The New York Times. She ended up placing in the top 20 with her story about the possible benefits of social distancing…that “after this experience, we can better understand how individuals who are continuously ostracized by society feel on a daily basis” and to learn that “empathy is more important than fear.”

Note: This is not an exhaustive list. Check out the Resource page on FIRST’s website (firstskinfoundation.org/resources) to learn of other books and articles written by our members. If you’ve written a book or article that we missed, please contact the FIRST office, so we can add your book to our site.

Carlie Foulks of Tennessee, reads “See My True Colors” by Jessica Wu to teach children that there is beauty in our differences.

Another Face of Rare Disease: Growing Up in the Dermatologist's Office

by Lindsey Herndon

At around 6 years old, my little brother, Matthew, was diagnosed with Darier's disease, a rare genetic skin disorder. Even after the diagnosis was reached from observing his visible symptoms, my brother had two skin biopsies and several second opinions from specialists to confirm this was indeed his condition.

My parents were used to this process though–when my brother was an infant he was diagnosed with celiac disease, way before eating gluten-free was trendy. He had dozens of examinations and blood tests before someone threw a celiac test into the mix on a whim, and it came back a shocking positive. After the diagnosis, his celiac disease was manageable–clear diet change and long grocery store trips spent diligently checking nutrition labels.

The Darier's, on the other hand, has proved to be an unsolvable puzzle that they're still trying to piece together.

Darier's disease is caused by a single gene mutation that leads to the production of a thick, dark rash commonly appearing on the chest, neck, and forehead. Textbooks say it presents as a collar around the neck, and that symptoms are worst in adolescence.

As Matthew's rash grew thicker and started to extend up his chin and cover his forehead, it became impossible to hide under swim shirts, baseball caps, and polos. No kid should have to explain to their teachers why their skin looks like it's on fire, convince their classmates that it isn't contagious, and learn to not pick at their face despite how incredibly uncomfortable they are. Middle school is tough enough trying to navigate hormones, school, and friendships, so adding this condition to the mix was incredibly difficult.

I played a passive role in his journey with the disease because I had my own growing up to do, but I was acutely aware of how it affected our family dynamic and my brother's personality. I saw my parents struggle with a rotating cast of specialists and the never-ending search for an effective treatment. They would work with a dermatologist until they thought there was nothing new for them to try, then would find another who hopefully had some key new piece of information.

> **“I watched the tides of hope and frustration come in and out as they tried new [treatments] in hopes for relief.”**

Back then and today, the real issue is that the rarity of the disease means there's not a lot of research happening. I watched the tides of hope and frustration come in and out as they tried new pills, creams, and diet changes in hopes for relief. Nothing helped significantly, and some regimens were just too much to ask of a teenage boy. I have clear memories of family movie nights turning into half-hour clay masks and ointment treatments; some itched, some burned, some smelled horrible, and all were nearly torture for him as he just wanted to spend time playing games or with his friends.

Lindsey Herdon and her brother Matthew

Not only was the lack of efficacy difficult for them to navigate, but the financial strain and the intense side effects weighed very heavily. Early teenage years are tough enough for your mental health, but add a pill with intense side effects and you get a very scary and sad situation. Having to choose between my brother's mental health and relief of this disease was not a choice my mother should have had to make, and not something my brother should have had to endure.

Bright moments came from our trips to the beach. We found that Matthew's skin loved the humid, salty air, and after a few days the rash would quiet down. Florida, Mexico, the Bahamas, those weeks away were escapes we treasured. We've both aged into adulthood now. My brother is graduating from college this May, but the Darier's is still there. He's sporting an impressive beard these days that hides some of the most noticeable areas, but the search for new specialists and new treatments will continue.

The burden of carrying the disease is transitioning from the shoulders of my parents to the shoulders of my brother, but my parents will always share that weight with him. My brother is one of the strongest people I know. He's grown into a confident, charming, and crazy smart man despite the emotional and physical challenges he has faced his entire life. He has achieved so much and will continue to do so.

Loving, and Being Loved, Unconditionally

by Angela Lowry-Sellers

I was blessed to be born to two great parents as the baby of four girls. My parents always made sure I was treated in the same way as my siblings, who are unaffected. My family made sure that my ichthyosis didn't define me, but that I defined it, by remaining socially active in church and school throughout my childhood years where I formed authentic loving friendships. My parents emphasized strength in my character and respect for those around me, and made sure I excelled.

Being a parent with ichthyosis was scary in the beginning. When I had my first child in 1988, I was very concerned as to whether he would have ichthyosis. I often contemplated what it would be like to have someone, a baby of my own, that looked like me. But I also knew that living with ichthyosis can be an extremely difficult life to live. When my son was born, he was perfect – not because he didn't have ichthyosis, but just because he was mine. Five years later, I gave birth to twins — healthy and perfect!

> **“My parents emphasized strength in my character and respect for those around me, and made sure I excelled.”**

As a parent, I often worried about them going to school and having to explain their mother's condition to their peers or teachers. What if someone asked them uncomfortable questions? What if they got teased or bullied? I didn't let it deter me, however, because it was important to me to remain active with their school. I made sure I was at every game, performance, or activity that they were involved in. I had very few incidents where I had to explain my skin condition. My children were very happy and active, and they never once told me that they were being teased about how their mother looked. Although they learned the importance of having good manners in church, school and home, I also believe my children learned innately how to be more compassionate to strangers or those who are different from us.

I feel very blessed to be raised in an environment where I was accepted. My son and my twins, now adults, are so proud of me and have never felt ashamed that I was their mother. Not to mention my precious five grandchildren whose favorite term of endearment is “Mawmaw” — they are my prize possessions! The blessings of great parents and siblings, a loving husband, awesome children, and adorable grandchildren overshadow the unkindness of a world that I have to face daily living with ichthyosis. Their unconditional love is what keeps me afloat and brings such great joy to my life.

Angela Lowry-Sellers poses with her grandchildren

FIRST wants to hear from you!
Send us your stories, letters or art and we may feature you in a future issue.
info@firstskinfoundation.org

Learning to Love the Skin I'm In

by Tijuana Akers

I was born with and live with a rare condition called palmoplantar keratoderma (PPK). PPK is caused by a genetic mutation that results in abnormalities of keratin in the body.

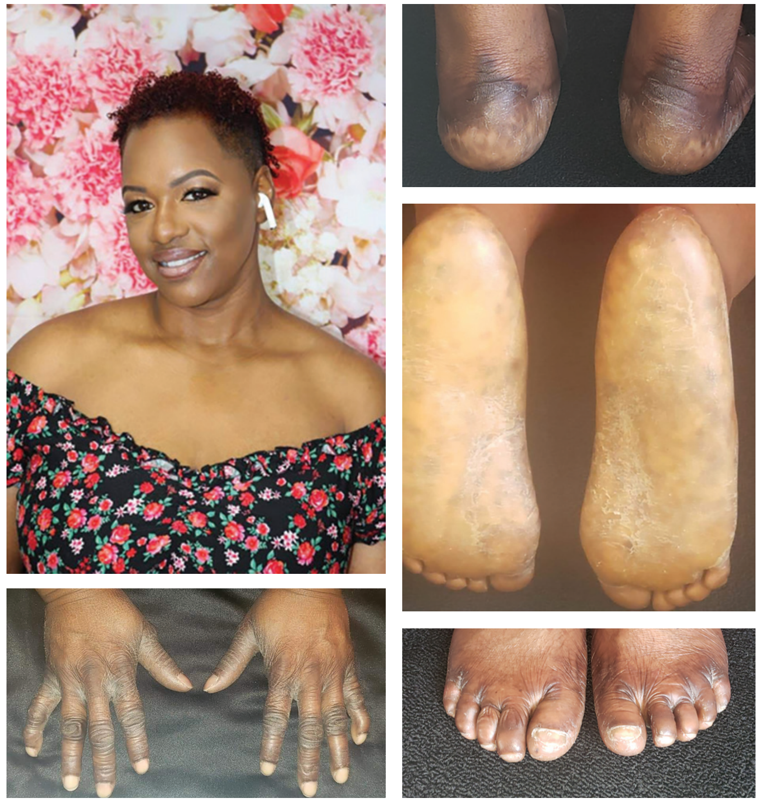
There is more than one type of PPK, and each has its own associated features dependent on the specific gene mutation. The common feature is thickened skin on the soles of the feet and palms of the hands. Severity can vary widely, even among family members.

The physical, mental and emotional toll of PPK cannot be understated. It has affected every aspect of my life for as long as I can remember. I've been teased, bullied, ostracized, and treated like a leper at times because of my skin.

I deal with constant pain, stiffness, heightened sensitivity to cold, poor circulation, extremely dry, tight skin that is prone to peeling, cracks, deep fissures that resist healing, and infections. I have a slight deformity of joints and lack of mobility in my hands, feet, wrists and ankles. My toenails are thickened and hooked over the toes, another source of pain and discomfort.

Sometimes the pain in my feet gets so bad that walking is excruciating. It even limits the shoes that I am able to wear.

Sharing these pictures publicly is a form of liberation for me. No more hiding, no more fear of judgement – I'm learning to love the skin I'm in!



Tijuana is affected by PPK, which causes thickened skin on her hands and feet. She shares these photos to help others learn more about the condition.

Studies Advance Understanding of Infection, Treatment and Mental Health

Dr. Erin Mathes and Dr. Mitchell Braun from UC-San Fransisco summarize recently published research.

Dr. Erin Mathes

Dr. Mitchell Braun

Inherited ichthyosis and fungal infection: an update on pathogenesis and treatment strategies

Journal of the German Society of Dermatology; systematic review article, March 2021; Miao H, Dong R, Zhang S, *et al.*

Review: People with ichthyosis may have a higher risk of developing skin fungal infections compared to the general population. Authors of this article reviewed cases of fungal infections in ichthyosis over the past 50 years to summarize the causes, signs and symptoms, diagnosis, and treatments.

Summary: People with ichthyosis have more fungal skin infections than the general population and diagnosis can be difficult. Fungal infections should be considered in new or worsening hair loss, bumps, pustules, worsening scale, or changes to nails. If any of these symptoms arise, people with ichthyosis should discuss them with their primary care doctor or dermatologist.

Use of telemedicine for ichthyosis: patient advocacy group as conduit to expert physician advice

Pediatric Dermatology; retrospective cohort study, January 2021; Asch S, Swink SM, Vivar KL, *et al.*

Review: The expert panel reviewed a total of 88 cases referred to the FIRST Tele-Ichthyosis program from the United States, Canada, the Caribbean, South America, Europe, Africa, Asia, and the Middle East. The volunteer panel diagnosed ichthyosis in 66% of cases that were reviewed. About 2/3 of submitting physicians described the service as easy to use and reported timely, clear, and beneficial advice.

Summary: Some people with ichthyosis do not have local access to expert opinion. The FIRST Tele-Ichthyosis program provides these patients and their local providers with insights from a panel of ichthyosis experts. This program will continue providing advice on diagnosis, treatment, and other aspects of keratinizing disorders and serves as an example of how telemedicine can benefit treatment and care across the world for rare diseases.

Consensus recommendations for the use of retinoids in ichthyosis and other disorders of cornification in children and adolescents

Pediatric Dermatology; consensus recommendations, January 2021; Zaenglein AL, Levy ML, Stefanko NS, *et al.*

Review: Retinoids are vitamin A derivatives that work to reduce scaling and thickening of the skin in many ichthyoses and are essential to management. The impact of long-term retinoids on bone, eye, reproductive and psychiatric health were reviewed with the goal of creating recommendations for drug dosing and monitoring.

Summary: Topical and systemic retinoids are recommended for the treatment of ichthyoses and other diseases of cornification. The benefits of systemic retinoids often outweigh the risks, and regular monitoring for side effects is an effective measure in preventing long term impacts of these medications.

Increased risk of depression and impairment in quality of life in patients with lamellar ichthyosis

Dermatologic Therapy; cross sectional, January 2021; Cortés H, Rojas-Márquez M, Reyes-Hernández OD, *et al.*

Review: In this study, the investigators identified 26 people with Lamellar ichthyosis and 26 healthy controls from Mexico and used the Depression Beck Inventory II (DBI-II) and Dermatologic Life Quality Index (DLQI) to assess depression and impairment in QoL between the two groups.

Summary: LI is associated with higher rates of depression when compared to healthy controls and has a significant impact on quality of life regardless of disease severity. Mental healthcare is an important aspect of LI healthcare, and there should be regular discussions about mental health and wellbeing.

Read more research reviews at
firstskinfoundation.org/quarterly-research-literature-review

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OUR NEW ADDRESS! PO Box 1067 • Lansdale, PA 19446-0687

Conference Registration Now Open

Early bird registration for the 2022 National Conference is now open! Register before Dec. 31 to secure the best rates.

The conference will be held **June 24-26, 2022, in Providence, RI.**

Register now at firstskinfoundation.org/providence-2022

Full registration (13+): $250

Child registration (4-12): $140

Pre-K registration (1-3): $35

Registration costs include access to all conference sessions, evening entertainment and most meals. For full details, visit firstskinfoundation.org/providence-2022.

Once registered, please reserve your hotel room at the Crowne Plaza Providence-Warwick Airport Hotel. The conference room rate is $153 per night.

After two postponements due to the global COVID-19 pandemic, we are excited to bring our members together again!

FIRST National Conference 2022

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REGISTRATION AND FINANCIAL AID APPLICATIONS OPENED ON OCTOBER 1.

STAY TUNED FOR MORE ANNOUNCEMENTS COMING SOON!