

Reflecting on the World Patients Alliance Asia-Pacific Regional Meeting in Dubai by Edmund Lau

The World Patients Alliance (WPA) Asia-Pacific Regional Meeting which was held in Dubai from 4-5 November 2023 marked a significant milestone in global healthcare advocacy. I was deeply honoured to represent the Psoriasis Association of Singapore as a panellist, contributing to critical discussions on healthcare advocacy, equality, and accessibility.

The event in Dubai was an example of collaborative efforts in tackling the complexities of global healthcare systems and patient advocacy. The meeting's hybrid format allowed for both in-person and virtual participation thus ensuring inclusivity and global representation.

WPA's leadership, which includes Andrew Spiegel, Penney Cowan and Hussain Jafri, emphasized on the evolving role of patient advocacy and expressing gratitude to the global patient advocacy community.

I was involved in the session which focused on patients' access to medical treatments. The opportunity to discuss about how to break down barriers to accessing quality healthcare was enlightening and fulfilling. I was also entrusted with hosting a session to develop practical goals and strategies for the WPA in the Asia-Pacific region. We outlined short-term and long-term objectives for the WPA in order to achieve meaningful results and improve patient care standards in various health environments.

I am delighted to be appointed to the WPA's Asia Pacific Regional Steering Committee. This role involves working closely with the WPA's Board of Directors to identify and address key patient issues in the Asia Pacific region and formulate strategies that align with the WPA's mission and objectives. The Alliance' aspiration is that every patient can have access to safe, quality, and affordable healthcare services.

Insights from Distinguished Speakers

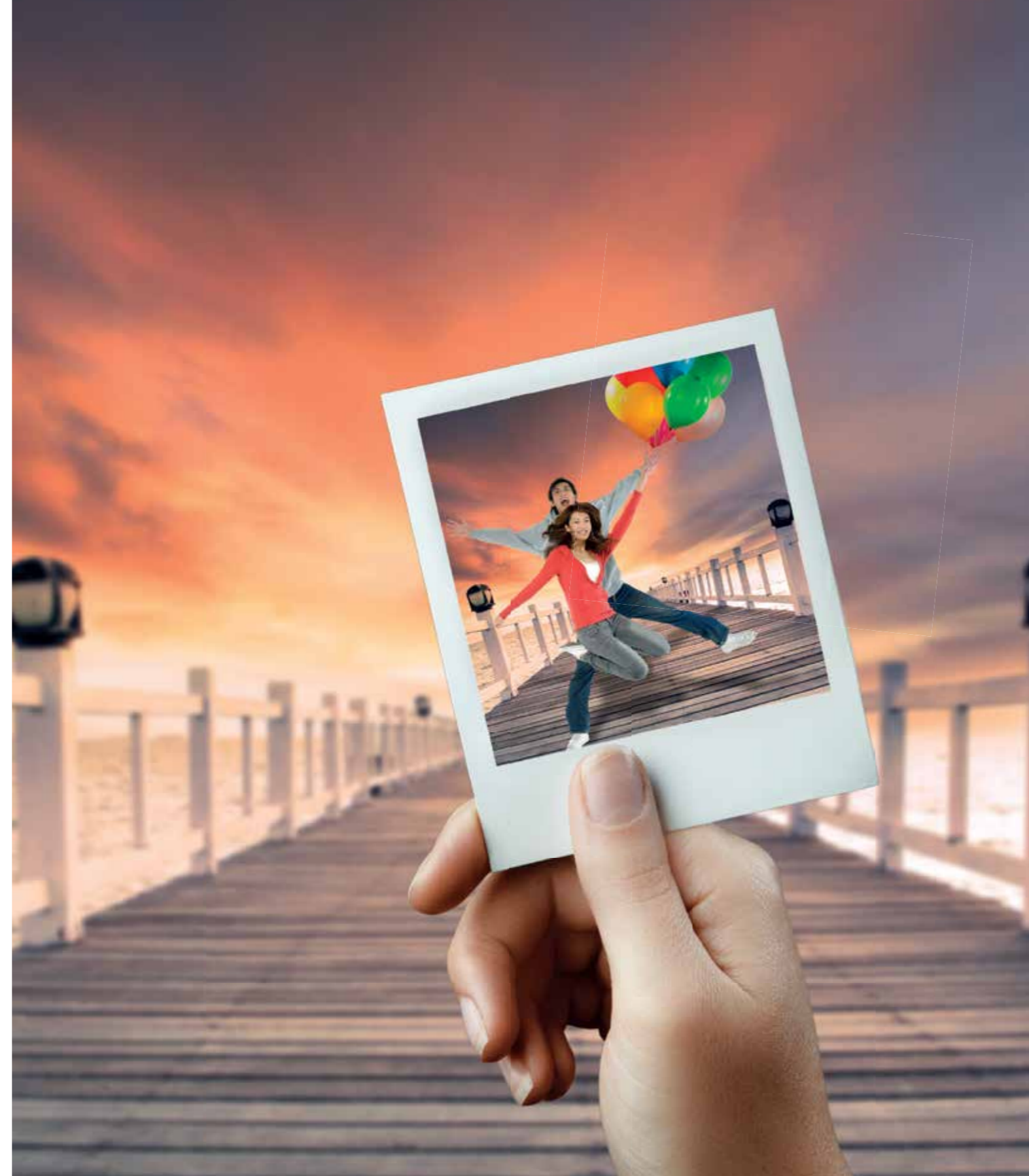
The event boasted a stellar line-up of speakers from national and international health organisations, each bringing their unique perspectives to the meeting. The speakers included Mondher Letaief, Shin Ushiro, Lamy Alhazani, Candace Henley, Christiane El Ferzli, Nicole Sheahan, Kimberly Galia, and the in-house speakers Andrew Spiegel Esq., Penney Cowan, and Hussain Jafri.

There were panel discussions featuring healthcare experts and patient safety champions. Anas Noufil, Ken Taneda, Edmund Lau, Areej Saqr, J S Arora, Mecciya Majrashi, Inge Dhamanti, and Regina Kamoga shared their experiences and perspectives on the future of patient safety and healthcare.

This gathering was more than just a meeting. It was a platform for building connections, exchanging best practices, and developing universally applicable healthcare solutions. It was also a celebration of the collective dedication to improving global healthcare.

We should stay engaged with the WPA for future updates, resources, and initiatives for a better global healthcare landscape.

Happy New Year to all of our members!



DKSH Singapore Pte Ltd (Reg. No.:200101487N)
47 Jalan Buroh, #09-01, Singapore 619491

OFFICE BEARERS (2023/2024)

President
Dr. Colin Theng

Vice President
Mr. Colin Binns

Secretary
Ms. Tan Yoke Choo

Asst Secretary
Ms Cassandra Loh

Treasurer
Ms. Alice Sin Kim Choo

Asst Treasurer
Ms. Siti Fatimah

Committee
Dr Koh Hong Yi
Mr Benjamin Goh
Mr Franky Yap
Ms Goh Ah May
Mr Ryan Chua
Mr Michael Pang
Mr Edmund Lau

Auditors
Dr. Eugene Tan
Mr. Wong Foot Keng

Editors
Dr. Tham Siew Nee
Dr. Koh Hong Yi
Ms. Tan Yoke Choo

Medical Consultants
A.Prof. Chong Wei Sheng
Dr. Eugene Tan
Dr. Hazel Oon
Dr. Koh Hong Yi
Dr. Lim Kar Seng
Dr. Pan Jiun Yit
Dr. Tham Siew Nee
Dr. Wong Su Ni
Dr Yew Yik Weng

Email: psoriasissg@gmail.com
Website: psoriasis.org.sg
Phone: 9005 8264
facebook.com/psoriasis.sg
tiktok.com/@psoriasissg
http://instagram.com/psoriasissg

Payment by PAYNOW'
UEN NOS:S82S0050HPAS

President's message Jan 2024

It's a new year again and I wish everyone a Happy New Year! Hope this year brings you good health and happiness.

I was reading the article on 'Psoriasis and Beyond: The global psoriatic disease study' on the IFPA website. This study was to explore the impact of psoriatic disease. In the study, they interviewed 4978 people from 20 countries. Only a third of the participants were aware of the association of psoriasis with psoriatic arthritis. Over 80 percent of the participants were unaware of the association of psoriasis with cardiovascular disease and diabetes. 82% percent of people had experienced stigma and discrimination. 59% of the participants were not involved in the treatment decision with their doctors. Many patients with mild disease also felt that it impacted their quality of life significantly.

The full report is available on the IFPA website. The study does highlight that psoriasis goes beyond the skin and that it is importance to understand the impact psoriasis on the different aspects of life. Speaking to your doctor and being involved in the decision making for you own treatment is important too. Knowledge and education about psoriasis is important and empowers you in the decision making process.

The Psoriasis Association of Singapore aims to increase awareness and education about the disease among its members and the public. Do look out and attend the programmes we are planning for the year. I am sure you will find them useful and be empowered to manage your psoriasis better.

We are also hoping to engage more youths to join our events and hoping to establish a youth group to cater for their needs. We are planning have support group meeting catered for youths to help them cope with stress of living with psoriasis. So to all youths out there, do contact us to indicate your interest in joining our events and association and we will be very glad to welcome you.

Stay safe everyone and hope to see you at our association's events.

Have a great year ahead!

God bless,

Colin Theng



World Psoriasis Day 2023: “A Day of Unity and Empowerment” by Edmund Lau

We, in Singapore, exultantly celebrated World Psoriasis Day 2023 at Kampung Admiralty, Community Plaza, a day marked by unity, learning, and a strong sense of community on 22 October 2023.

We extend our profound gratitude to Ms. Mariam Jaafar, Member of Parliament for Sembawang GRC, for gracing us with her presence. As our Guest of Honour, her enlightening presence added a layer of distinction to our event and emphasised the importance of inclusivity in healthcare.

Embodying the spirit of “Access for All”, the day was an embodiment of inclusivity, ensuring everyone feels supported and understood in their journey with psoriatic disease.

A standing ovation goes to Drs. Alex Chin, Ellie Choi, and Yingshan filled the venue with the heart-warming and uplifting power of music, enhancing the atmosphere of our gathering.

Dr. Ellie Choi also led a deeply insightful patient panel discussion where personal stories intertwined with professional advice, offering a rich discussion of experiences and treatment strategies.

Our gratitude extends to Dr. Colin Theng and Dr. Koh Hong Yi for their illuminating Psoriasis Talks in English and Chinese, respectively, broadening our horizons and enhancing our understanding of psoriasis.

A big “Thank you” shout-out to four medical students from Duke-NUS Medical School for volunteering and sharing their knowledge with the public using the interactive media panels.

Kudos to the dedicated registered nurses who professionally managed the health booths, providing essential services like Glucose Tests and Blood Pressure measurements.

The event was sprinkled with joy through vibrant balloon sculptures and the free flow of ice cream, bringing smiles and delight and making the day memorable for attendees of all ages.

Reflecting on a day filled with profound learning, community spirit, and warm connections, we are filled with gratitude for all of your active participation and presence.

Our heartfelt Thanks go to our Platinum Sponsors - AbbVie, DKSH, Boehringer Ingelheim, and Novartis. Your generous contributions ensured that we could continue to offer valuable health services to our community and create an engaging and educational environment for all our attendees.

We are equally Thankful for our Silver Sponsors - AMGEN and Janssen, whose support was vital in bringing life to the event with activities that delighted everyone present.

A special mention must be made to the Singapore National Skin Centre, ego, ADES, and National University Hospital for their unwavering support. Your collaboration has been instrumental in driving our message of awareness and support for those affected by psoriatic disease.

As we look ahead to World Psoriasis Day 2024, we carry with us the warmth and unity of this year’s event. Your support propels us forward in our mission to empower individuals with psoriasis, ensuring that no one has to walk their journey alone.

Thank you once again to every one of you for making World Psoriasis Day 2023 a success and a beacon of hope and camaraderie.

Wishing all a Happy New Year and looking forward to the continued journey with you.



Generalised Pustular Psoriasis Awareness and Befriender Recruitment Event by Ryan Chua

DEMYSTIFYING GENERALISED PUSTULAR PSORIASIS (GPP) FOR PATIENTS: Facts, Figures, and Realities

UNDERSTANDING GPP

- Rare chronic skin condition caused by deficiencies in the immune system
- Severe and potentially life-threatening
- Generalised means it impacts a larger skin area, and Pustular as it manifests as pustified bumps or pustules
- GPP cases can stem from IL-36RN genetic mutation. The gene is found in the skin, and regulates inflammation as the body's early immune response

IN SINGAPORE ALONE, 40,000 affected by psoriasis* 400 ARE GPP PATIENTS
GPP might be more prevalent than perceived. Often misdiagnosed as regular psoriasis, eczema, or skin infections

GPP DEMOGRAPHICS
Mainly seen in adults and starts between the ages of **40 - 59** and is more common in women than men. It can also occur in infants, young children, and adolescents.

RECOGNISING GPP: SYMPTOMS AND CHARACTERISTICS

Early symptoms

- Dry skin with burning sensation
- High fever and discomfort

Characterisation

- Recurring flares that emerge several times a year or every few years
- The nature of flares can include:
 - Sudden appearance of small pustules
 - Red patches on the skin surrounding pustules
 - Extreme pain, itching, and burning
- Lasts for 2-5 weeks

Additional complications

- Psoriasis psoriasis (scaly patches on skin)
- Inflammatory polyarthritis (swollen and painful joints)

Can lead to severe complications:

- Sepsis
- Pneumonia
- Liver damage
- Cardiorespiratory failure
- Kidney disorders

GPP SUBTYPES*

Acute GPP

- Highest risk of mortality
- Rapid widespread inflammation and pustule eruption
- Fever, chills, nausea, disrupted appetite, fatigue

Annular GPP

- Milder symptoms
- Lesions developing into ring-like pustules and red patches
- Pustules lasting less than a day

Pustular Psoriasis during pregnancy

- Eruption of red ring patches with non-infectious pustules
- Lesions within skin folds that spread rapidly

COMPARING GPP WITH PSORIASIS
GPP may be misdiagnosed as plaque psoriasis, which accounts for 90% of the psoriasis cases.¹⁰ However, GPP is more severe with **~50% higher mortality rate**

	PLAQUE PSORIASIS	GPP
APPEARANCE	Red patches of skin covered by silvery-white scales	Pustules surrounded by red skin
AFFECTED BODY PARTS	Scalp, trunk, limbs, elbows and knees?	Arms, legs, and trunk?
MANAGEMENT	Managed in an outpatient setting	Hospitalisation required

TRIGGERS FOR GPP FLARES

- Discontinuing steroids during plaque psoriasis treatment^{10,11}
- Taking systemic medications including pain and hormone therapies
- Sun overexposure
- Pregnancy
- Infections, stress, low calcium, upper respiratory tract infections

GPP: BEYOND SKIN DEEP STIGMA AND SUPPORT

DISPELLING GPP MYTHS TODAY FOR A MORE INCLUSIVE TOMORROW

GPP is not contagious!

- Not an infectious disease caused by bacteria or viruses
- Non-transmissible; GPP cannot be contracted from someone by:
 - Shaking hands, including hands with lesions
 - Sharing food and drinks
 - Engaging in intimacy

GPP is not a reflection of poor hygiene or lifestyle choices!

- GPP is involuntary, caused by deficiencies in the immune system
- Symptoms appear despite patient seeking treatment; GPP has no cure yet

MENTAL HEALTH*

- experienced fear, anxiety, and were worried about loss of medication effectiveness

SLEEP*

- 90% experienced poor sleep quality
- 38% experienced clinical insomnia

WORK AND PRODUCTIVITY

- 27% stopped working
- Economic burden of GPP in Singapore -SGD 18,705¹² (hospitalisation and treatment and prescribing therapy)
- 65% reduced ability for household activities

DAY-TO-DAY ACTIVITIES

- 6 out of 10 impaired physical activity
- 4 out of 10 reduced ability for household activities

SOCIAL LIFE*

- 94% social life impacted
- 77% experienced stigma
- Distorted self-access
- Social avoidance
- Internalized stigma leading to self-stigma

OVERCOMING AND DESTIGMATISING GPP: HOW PATIENTS CAN MAKE A DIFFERENCE

- Seek effective GPP treatments**
 - Corticosteroid withdrawal after long-term usage can trigger flares
 - Traditional medicine or home remedies could worsen GPP
- Develop a holistic care plan**
 - Including emotional support, as regulating emotions can help to prevent flares
- Engage in conversations**
 - Destigmatised GPP
 - Encourage empathy
 - Foster inclusivity

CONNECT FOR SUPPORT AND MORE INFORMATION ON GPP/PSORIASIS

Join a support group:

psoriasis association of singapore

Helpline for urgent cases: +65 9005 8204

Committed to being your befriender throughout your Psoriasis Journey.

Scan the QR code to join our community today.

psoriasis association of singapore

*This infographic has been made possible with the support of Boehringer Ingelheim Singapore Pte. Ltd.

Generalised Pustular Psoriasis Awareness and Befriender Recruitment Event by Ryan Chua

Event Overview: The Generalised Pustular Psoriasis Awareness and Befriender Recruitment Event, held on December 2, 2023, was a significant event to put the spot light on the rare and debilitating skin condition known as Generalised Pustular Psoriasis (GPP). This event aimed to increase awareness of GPP while also recruiting nurses as befrienders to provide crucial support for patients dealing with this challenging condition. Approximately 25 dedicated nurses attended the event, making it a meaningful and productive gathering.

Event Highlights:

- Educational Sessions:** The event kicked off with informative sessions on Generalised Pustular Psoriasis. Leading dermatologists and medical professionals provided an in-depth overview of the condition, including its causes, symptoms, and treatment options. Attendees gained valuable insights into the challenges faced by GPP patients.
- Patient Testimonials:** The personal experiences of GPP patients played a pivotal role in the event. Several individuals shared their journeys of living with GPP, highlighting the physical and emotional toll it takes on their lives. These testimonials added a human touch to the event and underscored the importance of support from healthcare professionals.
- Befriender Recruitment:** One of the primary goals of the event was to recruit nurses to serve as befriender for GPP patients. Nurses in attendance had the opportunity to learn about the role of a GPP befriender, which includes providing emotional support, assisting with treatment adherence, and helping patients navigate the healthcare system.
- Networking Opportunities:** The event provided ample networking opportunities for nurses to connect with fellow professionals, dermatologists, and patient advocates. These connections will serve as valuable resources in their work to support GPP patients.
- Resource Hub:** An information booth was set up to provide attendees with pamphlets, brochures, and other resources related to GPP. Nurses could access educational materials to enhance their understanding of the condition and its management. This allowed nurses to gain practical knowledge and skills that would be invaluable in their roles as befrienders.
- Q&A Panel:** A panel of experts took questions from attendees, addressing queries about GPP, its treatment options, and the role of befrienders in patient care. This session fostered a dynamic exchange of knowledge and ideas.

Conclusion: This event was the collaboration with Dermatology Nursing Chapter of Singapore Nursing Association and sponsored by the Boehringer Ingelheim. The event succeeded in creating a platform for education, collaboration, and networking among healthcare professionals, patient advocates, and individuals affected by GPP. This event marked a promising beginning in the journey to improve the lives of GPP patients.

