

# 2024 Board of Directors - Election Candidates

<b>Applicant</b>	<b>Organization</b>	<b>Region</b>	<b>Disease Area</b>
<b>Marie-France Bru-Daprés</b>	Association Française pour la Recherche sur l'Hidrosadénite	Africa	Hidradenitis Suppurativa
<b>Guillermo Gutierrez</b>	FUNDAPSO	Americas	Multiple Diseases
<b>Gaylord Inena Wa Inena</b>	Corbetta DRC	Africa	Albinism
<b>Ritu Jain</b>	DEBRA Singapore	Eastern Mediterranean	Epidermolysis Bullosa
<b>Ghulam Mustafa</b>	Helping Hands Foundation	Eastern Mediterranean	Multiple Diseases
<b>Noel Ntawigaya</b>	Promotion of Education Link Organization (PELO)	Africa	Albinism
<b>Holly Priebe</b>	Cutaneous Lymphoma Foundation	International	Cutaneous Lymphomas
<b>Christina Raj</b>	Center For Ichthyosis Related Members Foundation India	South-East Asia	Ichthyosis
<b>Toni Roberts</b>	DEBRA South Africa	Africa	Epidermolysis Bullosa

# Marie-France Bru-Daprés

Association Française pour la Recherche sur l'Hidrosadénite – President  
and Founder  
*Africa Region*



## **Why do you want to be elected to GlobalSkin's Board of Directors?**

I am deeply motivated to join GlobalSkin's Board of Directors, driven by my passion for empowering dermatology patients worldwide. GlobalSkin's mission to support and strengthen patient organizations in dermatology aligns perfectly with my values and goals. As a board member, I am committed to advocating for patients' rights and ensuring equitable access to quality dermatological treatments and care. Drawing on my experience and understanding of the challenges faced by dermatology patients, I aim to collaborate with fellow board members to develop innovative initiatives addressing patients' evolving needs globally. Furthermore, my dedication to raising awareness among the public and policymakers will amplify the patient voice and underscore the importance of dermatological care for overall health and well-being. Joining GlobalSkin's Board of Directors, I pledge to bring my energy, skills, and determination to support the organization's mission and advance the cause of dermatology patients worldwide. I am eager to contribute to positively impacting the lives of these patients and playing an active role in realizing GlobalSkin's vision.

## **What expertise and experience would you contribute to achieving GlobalSkin's mission in your role as a Board Director?**

As a retired Clinical Research Associate and founder of AFRH, I bring extensive experience in patient advocacy and healthcare innovation to GlobalSkin's Board of Directors. My leadership in organizing the first international medical congress on Hidradenitis Suppurativa (HS) in the Indian Ocean in 2023 demonstrates my ability to drive impactful initiatives within the medical community. I am proud to have initiated the World Day on Hidradenitis Suppurativa and the awareness month "June Violet," shedding light on this under-recognized condition. These efforts underscore my commitment to raising awareness and improving access to care for dermatology patients worldwide. My role in spearheading these initiatives aligns closely with

# Marie-France Bru-Daprés

Association Française pour la Recherche sur l'Hidrosadénite – President  
and Founder  
*Africa Region*



GlobalSkin's mission to empower patients and strengthen dermatology organizations globally. I am dedicated to leveraging my expertise in clinical research and patient advocacy to advance the organization's vision of inclusive and equitable healthcare. In summary, my experience in clinical research, patient advocacy, and healthcare leadership positions me to contribute to GlobalSkin's mission. I am eager to collaborate with fellow board members to drive positive change for dermatology patients worldwide.

## **What are your strongest skill areas?**

- Communications/Public Relations
- Event Planning
- Program Development/Strategic Planning

## **Describe any experience you have in working with and/or on Boards of Directors.**

Having founded and led AFRH for 24 years, I possess extensive experience collaborating with and leading Boards of Directors. This involves strategizing, governance oversight, and fostering effective teamwork. I bring a deep understanding of board dynamics and decision-making processes, which I aim to leverage to contribute effectively to GlobalSkin's mission.

## **What GlobalSkin events and initiatives have you participated in?**

Last year, in 2023, I participated in 'Elevate,' an event organized by GlobalSkin Europe in Brussels. This experience provided valuable insights into GlobalSkin's initiatives and enhanced my understanding of their mission and goals.

Guillermo Gutierrez  
FUNDAPSO – Director  
*Americas region*



**Why do you want to be re-elected to GlobalSkin's Board of Directors?**

I would like to be re-elected because GlobalSkin is a very serious organization with highly defined principles. In addition, the board is comprised of professionals with exceptional human values who are working towards the benefits of all skin patients.

**What expertise and experience would you contribute to achieving GlobalSkin's mission in continuing your role as a Board Director?**

Having led Fundapso for the past 14 years, this has provided me with a vast array of experience and knowledge that I am more than happy to provide to the organization.

# Guillermo Gutierrez

FUNDAPSO – Director

*Americas region*



## What are your three strongest skill areas?

- Advocacy/Outreach
- Communications/Public Relations
- Program Development/Strategic Planning

## Describe any experience you have in working with and/or on Boards of Directors.

During my work with Alapso, I acted as vice president and lead the first LATAM Psoriasis Patient Survey. I am currently a part of the Fundapso Board of Directors in which I am responsible for elaborating, presenting and executing the national and Latin American projects.

## List the GlobalSkin events and initiatives in which you have you participated.

- IDIPOC 2015, Vancouver, participated as a speaker
- GlobalSkin 2019 Conference, Milan, I participated by supporting the event's organizing committee in logistics
- GlobalSkin 2023 Conference, Brussels, I participated as a member of the board of directors assisting in logistics

# Gaylord Inena Wa Inena

Corbetta DRC – CEO and founder  
Africa region



## **Why do you want to be re-elected to GlobalSkin's Board of Directors?**

I am reapplying because I would like to continue to bring my contribution and my expertise as head of an organization of patients living with dermatological diseases in Africa. Cultural, political and socio-economic conditions in Africa are very different from those of patients living on other continents. My re-election would enable GlobalSkin to truly be a global organization that integrates the realities and conditions of everyone.

## **What expertise and experience would you contribute to achieving GlobalSkin's mission in continuing your role as a Board Director?**

- I will bring my expertise as a doctor specialized in the management of dermatological and psychiatric conditions
- I will contribute with the knowledge acquired from EUPATI training during this ongoing cohort
- I will bring my expertise as leader of an association of people living with dermatological diseases in Africa (particularly in cultural, political and socio-economic conditions)
- I will bring my experience acquired during my first mandate as a board member

# Gaylord Inena Wa Inena Corbetta DRC – CEO and founder Africa region



## **What are your three strongest skill areas?**

- Advocacy/Outreach
- Event Planning
- Healthcare Administration/Policy

## **Describe any experience you have in working with and/or on Boards of Directors.**

I have gained a lot in terms of skills and knowledge in working on the board of an international organization with professionalism, transparency and inclusivity.

I like the experience of working with people with different backgrounds, different cultures and different socioeconomic status who are all committed to raising one voice; the voice of people living with dermatological conditions to increase their quality of life.

## **List the GlobalSkin events and initiatives in which you have you participated.**

- EUPATI ongoing cohort (2023-2024)
- World Congress of Dermatology, Singapore, 2023
- Data collection for GRIDD, 2023
- GlobalSkin African Regional Meeting, 2024

Ritu Jain  
DEBRA Singapore - President  
Eastern Mediterranean region



**Why do you want to be re-elected to GlobalSkin's Board of Directors?**

I would like to continue serving the board of GlobalSkin as well as the patient community living with various skin conditions globally. I hope to bring value through my first-hand experience of supporting family members living with a rare skin condition as well as my multiple roles in leading patient alliances (DEBRA International/Singapore, Rare Diseases International). In particular, I'm invested in representing and amplifying the voices of the marginalized and overlooked patients and patient alliances in the Asia Pacific regions and beyond that, the Global South.

**What expertise and experience would you contribute to achieving GlobalSkin's mission in continuing your role as a Board Director?**

I continue to bring my global and regional expertise in patient advocacy, unique disease/regional/cultural challenges to access to care and diagnosis, and my networks towards continuing and strengthening the work of GlobalSkin.



# Ritu Jain

## DEBRA Singapore - President Eastern Mediterranean region



### **What are your three strongest skill areas?**

- Community leadership
- Education/training
- Grant/proposal writing

### **Describe any experience you have in working with and/or on Boards of Directors.**

I have established and managed national level and regional patient alliances (DEBRA Singapore and APARDO) as well as chair DEBRA International. I also co-chair Singapore's national HTA consumer panel and serve on boards of other global organisations.

### **List the GlobalSkin events and initiatives in which you have you participated.**

WCD 2023, GlobalSkin side events (Geneva), GlobalSkin Conference 2023 – Elevate

# Ghulam Mustafa

[Helping Hands Foundation](#) – CEO

*Eastern Mediterranean Region*



## **Why do you want to be elected to GlobalSkin's Board of Directors?**

I am eager to join the GlobalSkin Board of Directors to further my commitment to advancing dermatology patient care and advocacy on a global scale. As the CEO of the Helping Hands Foundation, I have firsthand experience in leading initiatives that significantly impact patients' lives by improving access to treatment and raising awareness about dermatological conditions. My leadership has been instrumental in formulating strategic objectives and overseeing operational successes within a patient-centric framework. At GlobalSkin, I aim to leverage my expertise in nonprofit management and patient advocacy to enhance the organization's strategic direction and governance. My background equips me to offer valuable insights into financial strategy, risk management, and organizational compliance, ensuring long-term success and stability. Additionally, my experience working in diverse cultural contexts will support GlobalSkin's mission to foster inclusivity and diversity within the board and the broader dermatology community. My goal is to contribute to GlobalSkin's vision by ensuring that every decision and strategy aligns with the best interests of dermatology patients worldwide, making a meaningful difference in their healthcare journey.

## **What expertise and experience would you contribute to achieving GlobalSkin's mission in your role as a Board Director?**

As the CEO of the Helping Hands Foundation, I bring a wealth of experience in strategic leadership, financial oversight, and global health advocacy, directly aligning with the duties of a GlobalSkin Board Director. My background in managing a patient advocacy organization has deepened my understanding of dermatology patient care challenges, particularly in resource-limited settings. I have a proven track record in strategic planning, enhancing operational efficiencies, and ensuring compliance with legal and regulatory standards. My financial acumen has been key in securing sustainable funding and maintaining fiscal health, skills critical for guiding GlobalSkin's financial strategy. Additionally, my extensive work across diverse cultural landscapes equips

# Ghulam Mustafa

[Helping Hands Foundation](#) – CEO

*Eastern Mediterranean Region*



me to help GlobalSkin expand its global impact, ensuring that our strategies are inclusive and representative of all demographics. Committed to the principles of diversity and inclusion, I aim to foster an environment that echoes GlobalSkin's mission to enhance the quality of life for dermatology patients worldwide. My expertise and experience are geared towards driving our shared vision forward, making a tangible difference in the healthcare journeys of dermatology patients globally.

## **What are your three strongest skill areas?**

- Community Leadership
- Education/Training
- Event Planning

## **Describe any experience you have in working with and/or on Boards of Directors.**

With over 21 years of leadership experience at the Helping Hands Foundation, including seven years as Chairman and 14 years as CEO, I have extensive experience working with and on Boards of Directors. My roles have involved strategic planning, financial oversight, and governance, ensuring organizational alignment with our mission and compliance with legal standards. I have successfully led board meetings, facilitated board development and succession planning, and have been deeply involved in decision-making processes that have significantly shaped the direction and impact of the organization.

## **What GlobalSkin events and initiatives have you participated in?**

I have actively participated in GlobalSkin's advocacy campaigns, contributing to raising awareness and advancing the interests of dermatology patients worldwide. Additionally, I have engaged in multiple online seminars, enhancing my knowledge and network within the dermatology community. Most notably, I attended the in-person conference in Singapore in 2023, where I deepened my understanding of global dermatological issues and fostered collaborations with fellow professionals dedicated to improving patient care in the field of dermatology.

# Noel Ntawigaya

Promotion of Education Link Organization (PELO) – Key Board Member  
*Africa Region*



## **Why do you want to be elected to GlobalSkin's Board of Directors?**

I seek election to the GlobalSkin Board of Directors to represent the African region and bring the perspective of Promotion of Education Link Organization. Our organization is dedicated to safeguarding children's rights, including access to basic necessities like health care, education, and shelter, especially for those living in vulnerable environments, including individuals with albinism. As a Board Director, I aim to advocate for inclusive skincare solutions that address the specific needs of African communities. My background in championing fundamental rights aligns with GlobalSkin's mission to promote skin health worldwide. I believe my experience working directly with marginalized populations equips me to contribute meaningfully to the Board's initiatives. By serving in this capacity, I aspire to bridge gaps in access to dermatological care, foster collaborations with local stakeholders, and advance policies that prioritize equitable skin health outcomes across the African continent. Joining the Board presents an opportunity to amplify the voices of underrepresented groups and drive impactful change in global skin health initiatives. Moreover, this role aligns with my passion for promoting health equity and creating positive change on a global scale.

## **What expertise and experience would you contribute to achieving GlobalSkin's mission in your role as a Board Director?**

As a Board Director, I bring a wealth of expertise and experience that aligns with GlobalSkin's vision and mission. With a significant background of working with Promotion of Education Link Organization, dedicated to safeguarding children's rights and advocating for basic necessities such as healthcare and education, I possess a deep understanding of the intersection between health, socio-economic factors, and marginalized communities' needs. Specifically, my experience in managing projects focused on vulnerable populations, including individuals with albinism, equips me to address the unique challenges they face in accessing dermatological care and managing skin health issues. Furthermore, my network within African communities allows me to leverage local partnerships and insights to develop culturally sensitive and contextually relevant initiatives that promote skin health equity. Additionally, my advocacy

# Noel Ntawigaya

Promotion of Education Link Organization (PELO) – Key Board Member

*Africa Region*



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Dermatology Patient  
Organizations

work on fundamental rights positions me to effectively champion GlobalSkin's mission to advance dermatological care accessibility and address disparities worldwide. Overall, my blend of expertise in child protection, advocacy, and community engagement uniquely qualifies me to contribute to GlobalSkin's efforts in realizing its vision of a world where everyone has access to quality skincare, regardless of their background or circumstance.

## **What are your strongest skill areas?**

- Education/Training
- Advocacy/Outreach
- Program Development/Strategic Planning

## **Describe any experience you have in working with and/or on Boards of Directors.**

I have extensive experience working with Boards of Directors through my involvement in various non-profit organizations. As a member of the Promotion of Education Link Organization's leadership team, I regularly collaborate with our board to develop strategic plans, oversee organizational governance, and ensure alignment with our mission. Additionally, I have served on advisory boards where I provided input on program development and organizational growth strategies. These experiences have equipped me with a comprehensive understanding of board dynamics, governance principles, and effective decision-making processes, which I can leverage to contribute meaningfully to GlobalSkin's Board of Directors.

## **What GlobalSkin events and initiatives have you participated in?**

I have participated in GlobalSkin events and initiatives primarily through our organization's director, Mr. Julius Muungano, who has regularly involved us in GlobalSkin events. Additionally, I am looking forward to attending the upcoming GlobalSkin African Regional Meeting in Nairobi, Kenya, from April 18th to 20th, where I will represent my organization. This participation provides me with firsthand knowledge and insights into GlobalSkin's activities, priorities, and collaborations within the African region.

# Holly Priebe

[Cutaneous Lymphoma Foundation](#) – Chief Operating and Financial Officer  
*International*



## **Why do you want to be elected to GlobalSkin’s Board of Directors?**

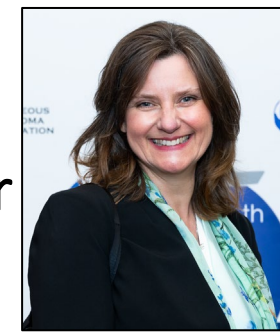
As a person living with multiple skin diseases in addition to working for the Cutaneous Lymphoma Foundation for over 20 years, I have come to deeply appreciate the value that GlobalSkin brings to people affected by skin diseases globally. I believe in the vision, mission, strategic goals and the values of GlobalSkin and would be honored to contribute and help to advance the mission of the organization.

## **What expertise and experience would you contribute to achieving GlobalSkin’s mission in your role as a Board Director?**

It would be my hope that with 20 years of skin-related nonprofit leadership experience along with my personal relationship with skin disease, that my passion and background would lend itself to be of value in many areas across the GlobalSkin Board. My background includes strategy, operations and finance along with an ongoing vision to develop new and innovative solutions to advocate for and empower a small global patient population.

# Holly Priebe

[Cutaneous Lymphoma Foundation](#) – Chief Operating and Financial Officer  
*International*



## **What are your strongest skill areas?**

- Finance/Accounting/Fundraising
- Not-for-profit Management
- Program Development/Strategic Planning

## **Describe any experience you have in working with and/or on Boards of Directors.**

Over my career at the Cutaneous Lymphoma Foundation, I have had the honor of working directly with our Board of Directors on strategic, annual and financial planning. I oversee the Finance committee and have served as the staff liaison on many other committees throughout the years. In addition to my role at the Foundation, I have also had the honor of serving as the Treasurer on the Coalition of Skin Diseases Board, as well as the President of the Japhet School parent Board of Directors.

## **What GlobalSkin events and initiatives have you participated in?**

The GlobalSkin Elevate 2023 Conference was my first in person conference with GlobalSkin. I have also participated in several webinars, member updates, and the past two AAD receptions, as well as had the honor to serve on the World Skin Health Coalition's Awareness Working Group.

# Christina Raj

[Center For Ichthyosis Related Members Foundation India](#) - Director  
*South-East Asia Region*



## **Why do you want to be elected to GlobalSkin's Board of Directors?**

I joined GlobalSkin in 2023, in few months I was invited for the most celebrated event Elevate 2023 in Brussels. I wasn't included or accepted in any group or organization before, but at Elevate, I was part of a different world, where I felt accepted as part of a community. For once I did not have to worry about skin, scales, greasy look. But, I learnt how to embrace my condition, be more confident. After attending Elevate 2023, I was treated with respect in my country. People started to listen to me, when I spoke about Ichthyosis. I started to travel around the country and reach out to other ichthyosis patients, because they cannot travel, as they are from under-privileged families with hardly any income to support other expenses. We ichthyosis patients are denied education, jobs and basic amenities in Asia. I was able to meet with Health Ministry officials in Feb 2024 to appeal to include Ichthyosis in rare disease list in India. If I get selected as a Director, I will connect with other patients in Asia and Africa. I can relate more closely with their pain; I can explain better about the condition and the challenges and pain we undergo.

## **What expertise and experience would you contribute to achieving GlobalSkin's mission in your role as a Board Director?**

This role is important, but so are the connections I make along the way. I am a people's person. I value time, people's effort and always ensure to stand up to their expectations. I believe relationships hold immense power in this world. They're the foundation that supports opportunities, collaborations, and growth. They provide a network of support that extends beyond the confines of our job titles. So this will help me strike the right balance in achieving our goal. Invest time in building and maintaining relationships with everyone. I believe that genuine conversations, practicing active listening, and offering support will cultivate a network that values unique perspectives and expertise. I believe that sharing knowledge and experience with others not only contributes to their growth but also establishes me as a trusted and valued resource. True leaders are those who empower others to succeed.



# Christina Raj

Center For Ichthyosis Related Members Foundation India - Director  
*South-East Asia Region*



## **What are your strongest skill areas?**

- Advocacy/Outreach
- Education/Training
- Event Planning

## **Describe any experience you have in working with and/or on Boards of Directors.**

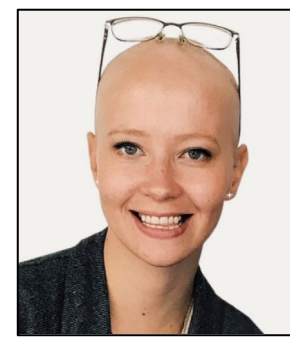
I was instrumental in helping an 18-year-old girl with lamellar aspires who wanted to study medicine. She got admission to college in another city, the Principal / college management refused to allot her a room in the hostel. The Principal said girl has contagious disease. The Principal was PhD, but still has low mindset. The girl was distraught and wanted to commit suicide. The girl's mother asked for my help. I called and spoke to the Principal, wrote an email to the management, shared her story on Facebook, Twitter and I shared Elevate pictures where I am with the world. This changed the Principal's attitude. Now, the girl tops every assignment.

## **What GlobalSkin events and initiatives have you participated in?**

My first event was an International Elevate 2023 at Brussels. I still relive those wonderful four days. I never knew the power we have within until IADPO make me realize my worth. I participated in 2023 online Events that were conducted. I was able to connect with more people. I was part of the GRIDD calls, had challenge as most are uneducated and below 13 years . I was privileged to be considered for the grant this year, this helped me with connecting with the Indian Government and appeal to include Ichthyosis in list of rare disease list in India.

# Toni Roberts

DEBRA South Africa – Chair  
*Africa Region*



## **Why do you want to be elected to GlobalSkin’s Board of Directors?**

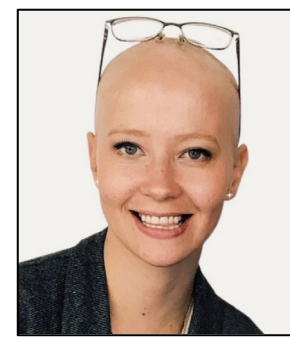
I would like to be elected to GlobalSkin’s Board of Directors for several reasons. Firstly, I feel that GlobalSkin has held a pivotal role in the growth of our Organisation over the past eight years. Through this first-hand impact, I have developed a deep passion for GlobalSkin’s values and would consider it an honour to ‘pay it forward’ by serving on the Board of Directors. I would be glad to bring constructive insights to the working team – whether it be in member relations, program management, technology, operations or guidance through challenges and opportunities. Secondly, I believe I hold a wide range of experiences in working well with people from all walks of life, no matter their age, socio-economic situation, geographical location, etc. There is a fine line between meaningful friendship, passion for community and constructive organisational outputs and over my years in volunteering in different organisations I believe I’ve learnt to balance these well. Finally, I have a genuine desire to make a positive impact, not only within GlobalSkin but across the patient landscape globally, collectively influencing decisions that shape the organisations’ impact and societal contributions. Overall, my candidacy reflects dedication, a colourful skillset, and authentic passion.

## **What expertise and experience would you contribute to achieving GlobalSkin’s mission in your role as a Board Director?**

As a potential Board Director for GlobalSkin, I would bring expertise and experience from both local and international settings in patient advocacy, healthcare knowledge, and member engagement, providing insights into the unique needs and perspectives of the patient community while ensuring adherence to ethical standards and transparency in organizational operations. My experience in project management and innovation equips me to navigate challenges and seize opportunities, fostering adaptive strategies that would keep GlobalSkin responsive to evolving patient needs and changing healthcare landscapes. Collaboration with diverse stakeholders ensures inclusive environments where all voices are valued. Additionally, my commitment to diversity, equity, and inclusion principles fosters

# Toni Roberts

DEBRA South Africa – Chair  
*Africa Region*



practices that address the needs of all members of the patient community, ensuring that GlobalSkin's programs and services would remain accessible and relevant to everyone. I believe that my skill set would uniquely position me to contribute effectively to GlobalSkin's vision and mission as a Board Director, driving positive change in the patient-led sector.

## **What are your strongest skill areas?**

- Community Leadership
- Education/Training
- Event Planning

## **Describe any experience you have in working with and/or on Boards of Directors.**

Over the past ten or so years I have worked alongside a few South Africa-based organisational Boards of Directors. Namely, Help2Read (a literacy organisation for children), Hands With Words (a sign language organisation) and Life Line Western Cape (a counselling organisation). Since 2017 I have worked on the Board of Directors for DEBRA South Africa. More recently, I have been elected as the President of the Executive Committee of the DEBRA International Youth Council (a support initiative aimed at young adult patients). Lastly, I was voted onto the Working Group of the newly established African Regional Network of GlobalSkin.

## **What GlobalSkin events and initiatives have you participated in?**

DEBRA South Africa first joined GlobalSkin in 2017 as a full member. I have attended Conferences in Ferney Voltaire (2017), Milan (2019), online during COVID-19 (2021) and Brussels last year (2023). Over the years I have taken part in all RareDERM and GRIDD-related initiatives and serve on both of their Advisory Committees respectively. This year I have been representing GlobalSkin through the EUPATI Patient Expert Program and will graduate in October (2024). Lastly, I attended the GlobalSkin African Regional Meeting in Kenya (2024) and am eager to start working with the newly voted Working Group for the region.