



PAFLAR NEWSLETTER

OCTOBER - DECEMBER 2024

**Dr. Angela
Migowa:
From Kenya
To The World**



In This Issue



- 4** [President's Note](#)
- 5** [A Puzzle Solver's Journey from Kenya To The Global Stage](#)
- 7** [Dr. Jessica Perfetto's Multilingual Approach to Pediatric Rheumatology](#)
- 9** [Dr. Angela Migowa Is Igniting Hope in Pediatric Rheumatology](#)
- 12** [The Transformative Role of Telemedicine in Pediatric Care](#)
- 13** [Donation](#)
- 17** [4th PAFLAR Congress: A Celebrated Gathering in Tunisia](#)



NOTICE BOARD

CME

We recently hosted a successful CME on hyperimmunity in Pediatric Rheumatology, featuring a keynote by Prof. Reem A. Mohammed (Egypt) and moderated by Dr. Jan Rene Nkeck (Cameroon). If you missed it, the recording is available on the PAFLAR website.

MANUSCRIPT

The first published manuscript from the JIA Registry is now available on our website.

PARTNERSHIPS

We are embarking on an exciting partnership with Cincinnati Children's Hospital on an ANA Testing Project. To stay updated on such initiatives, become a PAFLAR member.

PAFLAR'S 5TH CONGRESS

Be on the lookout for announcements regarding PAFLAR'S 5th congress, set to be held next year in Lagos, Nigeria.

WORLD ARTHRITIS DAY

Join PAFLAR as we celebrate World Arthritis Day on October 12, 2024. Follow us on social media to be part of the initiative.



PUBLISHED BY

Paediatric Society of the
African League Against
Rheumatism (PAFLAR)

Editorial

Prof. Angela Migowa

Design and Layout

Custom Media House
custommediahouse.com

Contributors




Dr. Angela Migowa




Dr. Francis Fredrick

Anthony Odallo

Anthony Kuria

Follow Us

-  Paflar Africa
-  Paflar Africa Afrique
-  @paflar

-  info@paflar.org
-  +254 722 841 719
-  paflar.org



PRESIDENT'S NOTE

Dear Readers,

I am thrilled to welcome you to the second issue of our PAFLAR newsletter. The overwhelming response to our first issue has been incredibly encouraging, and I know many of you have been eagerly awaiting this edition.

Pediatric rheumatology is a field rich with stories that need to be told—stories of resilience, innovation, and the relentless pursuit of better outcomes for our young patients. That is why PAFLAR is dedicated to sharing these narratives and shining a light on the vital work being done in our community.

I want to extend my deepest gratitude to pediatric rheumatologists from all over the world for their continued efforts and priceless contributions. Your dedication and hard work are making a significant impact in the lives of children and families affected by rheumatic diseases.

A special thank you to our respondents for this issue: Dr. Jessica Perfetto and Dr. Aarat Patel, and Dr. Francis Fredrick for his contribution on Role of

Telemedicine in Pediatric Care. We are grateful for the time you have taken to share your insights and expertise, enriching this publication with your contributions.

I am also pleased to report that the 2024 Congress in Tunis, Tunisia, was a resounding success. This Congress provided a platform to delve into both foundational and cutting-edge topics in pediatric rheumatology, offering our community invaluable opportunities for networking, idea sharing, and fostering new connections. We were honored to feature distinguished speakers and experts from around the globe, whose insights have further enriched our understanding and practice.

Looking ahead, I am excited about the future of our newsletter and the stories we will continue to tell. Thank you for your ongoing support and engagement. Together, we will continue to advance the field of pediatric rheumatology and make a lasting difference in the lives of the children we serve.

A Puzzle Solver's Journey from Kenya To The Global Stage

Text By Anthony Kuria
anthony@custommediahouse.com

From his early days in Kenya, to his current role as a pioneering pediatric rheumatologist in the United States, Dr. Aarat Patel's path is marked by dedication. Balancing his practice between Richmond and Charlottesville, and contributing significantly to global health through the Paediatric Society of the African League Against Rheumatism (PAFLAR) network, Dr. Patel is committed to advancing treatments for autoimmune diseases and improving patient care worldwide.

Nairobi is a city of contrasts: where a bustling metropolis and tranquil nature coexist harmoniously. This vibrant landscape, full of life and fervor, is where Dr. Aarat Patel's story begins.

Born and partly raised in Kenya, Dr. Patel's childhood was marked by the warmth of family and the challenges of a rapidly changing environment. His mother, a dedicated nurse working in Nairobi Hospital, instilled in him a profound respect for the medical profession. Her compassion and resilience would later inspire him to pursue a career in medicine,



specifically rheumatology—a field as complex and multifaceted as the landscapes of his youth.

Aged two, Dr. Patel and his family relocated from Kenya to Zimbabwe, where they lived until they immigrated to the US when he was 10. The transition from Africa to America was a defining moment in his life, filled with opportunities and obstacles.

Settling in a new country, adapting

to a different culture, and pursuing a rigorous education were challenges that tested his determination. Yet, these experiences also shaped his character and fueled his passion for medicine.

Dr. Patel's journey through medical school was marked by an insatiable curiosity and a desire to solve the puzzles of the human body. His fascination with the immune system and its myriad of diseases led him to specialize in rheumatology.

"During training, I enjoyed rheumatology cases because of the problem-solving aspect, critical thinking, and emerging treatments. The vast number of immune-mediated diseases are exciting to diagnose and manage," recalls the 45-year-old.

This passion was further nurtured during his fellowship at the University of Pittsburgh Medical Center and UPMC Children's Hospital of Pittsburgh, where he encountered some of the leading specialists in the field.

Dr. Patel's fellowship was not just a period of intense learning but also a time of significant professional development. "I was lucky enough to have a robust adult and pediatric training program. The training was top-notch because there were subspecialists who focused their patient care and research on one disease state. This made them experts in that part of the field," he explains.

However, the path was not without its hurdles. As a dual-trained specialist in internal medicine and pediatrics, Dr. Patel had to navigate the complexities of creating a dual fellowship program, which required approval from the Board of Internal Medicine and the Board of Pediatrics. His perseverance paid off, allowing him to gain a unique perspective on treating adult and pediatric patients with autoimmune diseases.

Today, Dr. Patel holds dual roles at Bon Secours Mercy Health in Richmond and the University of Virginia in Charlottesville. His practice spans a diverse patient demographic, allowing him to treat adults and children. "Pediatric patients are considered more

urgent. The body is growing, and those with arthritis can have significant damage if not controlled early in their disease," he notes. This dual focus not only enhances his expertise but also underscores his commitment to comprehensive patient care.

In addition to his clinical practice, Dr. Patel is actively involved in research. "I try to do a few clinical research projects every year," he says.

His interest in conditions such as dermatomyositis and Juvenile Idiopathic Arthritis (JIA) keeps him at the forefront of advancements in the field. "In myositis, we are using many more DMARDs and biologics than 15 years ago when I was in training. The same is true for JIA, the treatment options are growing," he remarks.

Dr. Patel's dedication to pediatric rheumatology extends beyond the United States. As a member of the scientific committee at the PAFLAR network, he has made significant contributions to the field. "Being part of the meeting and not just attending has shown me how much work it takes for the organizers to put together such a spectacular event that involves an entire continent," he reflects.

His presentations at PAFLAR have covered a range of topics, from skin findings in autoimmune diseases to the treatment of chronic recurrent multifocal osteomyelitis (CRMO).

Looking ahead, Dr. Patel envisions a future where PAFLAR partners more with other rheumatologic societies worldwide. "More collaborations with other rheumatologic societies across the world," he suggests, "are essential for advancing the field."

He is particularly excited about the potential of comparative effectiveness research in Africa,

especially with the introduction of JAK inhibitors that do not require refrigeration. This, he notes, is an innovation that could revolutionize treatment in resource-limited settings.

However, Dr. Patel is aware of the fact that there are major differences in the practice of pediatric rheumatology in the US compared to Africa. "The resources are limited in some African countries. The medicines are not available like they should be. We are however working to change some of this."

He adds that for Africa to overcome these challenges in the treatment and diagnoses of rheumatic diseases, especially with very few pediatric rheumatologists, there is a need to take advantage of technology. "The world is much smaller now with technologies like virtual visits and tele-consults."

On a personal note, Dr. Patel is not only a dedicated physician but also a devoted family man. He is married with three children—a 10-year-old daughter and two sons, aged 12 and 14. "I hope one of them will study rheumatology!" he says, expressing his desire for at least one of his children to follow in his medical footsteps.

Does he have plans or aspirations to return to Kenya to practice medicine in the future? "Perhaps when my children are out of the house," he says.

As Dr. Patel looks to the future, he remains committed to advancing the field of pediatric rheumatology, driven by the belief that: It is in the great unknown where new treatments and even diseases are discovered.

Dr. Jessica Perfetto's Multilingual Approach to Pediatric Rheumatology

Text By Anthony Kuria
anthony@custommediahouse.com

In the field of pediatric rheumatology, Dr. Jessica Perfetto stands out not only for her clinical expertise and research contributions but also for her dedication to bridging global disparities in healthcare. Fluent in Spanish, French, and Italian, Dr. Perfetto's linguistic abilities have enhanced her professional interactions and research collaborations, making her a key figure in international medical initiatives. Currently a fellow at The Children's Hospital at Montefiore and a master's candidate in Clinical Research Methods at Albert Einstein College of Medicine, Dr. Perfetto is deeply involved with the Paediatric Society of the African League Against Rheumatism (PAFLAR). Her experiences working with diverse populations and her commitment to equitable healthcare are profoundly inspiring. In this Q&A, Dr. Perfetto shares personal anecdotes, innovative ideas, and her vision for the future of pediatric rheumatology.

If you could go back in time and give one piece of advice to your younger self at the start of your medical career, what would it be and why?

I'd tell myself to be more open-minded and explore as many specialties as I can. Many areas of medicine are covered only very quickly, or not covered at all, and you

won't know if you like them unless you try to rotate in them and learn more about them. I also would advise myself to try to understand what life is like as an attending in your field of interest, not just thinking about the subject matter of the specialty itself. I would try to think about things like job availability, outpatient vs inpatient, consults, and whether the field requires you to work at an academic center, among others. I think these end up being parts of your specialty that are also important but that I hadn't thought about as a trainee.

Please share a specific patient story that profoundly impacted you and shaped your approach to pediatric rheumatology?

I have a teenage boy with Juvenile Idiopathic Arthritis (JIA) who came to us from the Dominican Republic near the start of my fellowship. He had such extensive and limiting contractures – where his joints were stuck in a certain position and could barely move. It turned out he had symptoms for the last eight to nine years but was not referred to a rheumatologist back home, therefore he was never diagnosed with JIA. While he is doing much better now and has not had active inflammation, he will probably never gain back a lot of the function in his joints. Certain things are physically hard for him to do. It sometimes can be very psychologically hard for him to feel so stuck, physically

and metaphorically. It is especially heartbreaking when I think of all the excellent and effective treatments we have for JIA. If he had grown up in a place where there was more familiarity with JIA and easier access to a pediatric rheumatologist, he probably would have had a very different outcome. Sadly, his story is not unique – there are so many children out there with similar stories, some of whom have diseases that are even more severe and life-threatening. It feels deeply unfair and unjust that some children do not have the same chance to get better as others, simply based on where they live. Trying to make care more equitable for all children, wherever they live, is something I care deeply about and that has been a major driver for me.

What unconventional methods or technologies do you think have the potential to revolutionize pediatric rheumatology in the near future?

This is not the most original of answers, but definitely Artificial Intelligence (AI). I was slow to get on the ChatGPT bandwagon but I think it has incredible potential to lessen the burden of certain important tasks that can help improve patient care. For example, I've been impressed by how ChatGPT has helped with letters of medical necessity for insurance companies to appeal a medication that was denied. By feeding it depersonalized information, it provides a well-written

structure for a letter with pretty good justifications. It has saved me a lot of time. It has also been really helpful with research. While I have some basic knowledge of statistical coding, there are many times when I get stuck with an error code I can't figure out. Previously, I would get lost in Google searches trying to find an answer. Now, I explain what I'm doing and copy the code and ChatGPT teaches me how to correct my code. It's incredible! It's like having a personalized teacher.

How do you envision leveraging global collaborations to address disparities in pediatric rheumatology care between developed and developing countries?

I was very lucky at the start of my fellowship training to be introduced to and connected with Drs. Angela Migowa, Kate Webb, and Chris Scott by Dr. Laura Lewandowski. Everything grew from there and led to more connections and becoming more involved with PAFLAR, being lucky enough to travel to Nairobi (Kenya) and Cape Town (South Africa) to work on collaborative research, and attending the PAFLAR Congress. With each of these, I have met more people from around the world who share a common interest in trying to make pediatric rheumatology care more equitable. We are very privileged in places like the United States to practice in well-resourced academic hospitals and to be supported by well-resourced research networks. However, these require time

and financial resources. I hope that countries that are lucky to have so many resources can consciously and proactively work together with less-resourced areas. I think all of us as pediatric rheumatologists want all children with pediatric rheumatic diseases to have the best care and outcomes possible. But if we think only of the children in our own countries, there will be many children who are not getting the care they need and deserve to live

healthy and fulfilled lives. I hope that we reach a place in the future where large international organizations are conscious about including providers, patients, and caregivers from all regions of the world and all resource settings in most, if not all, projects. Often it feels like we are doing similar work in parallel in different areas of the world, and I think our efforts would be so much stronger if we all came together and worked together. Part of this is also really listening to each other and understanding what the unique needs are in different parts of the world.

How has your work with diverse populations influenced your understanding and approach to treating pediatric rheumatic diseases?

Beyond differences in epidemiologic risk factors for particular diseases and certain complications of those diseases, working with diverse populations has helped me to understand how cultural differences can impact care. It's not as simple as prescribing a treatment and assuming a patient will take it. I've come to learn that some families have various beliefs that influence their approach to having a chronic illness and the resulting treatments. It's important to understand where a family is coming from and what is important to them so that you can make sure everyone is on board with the treatment plan.

How has your background in psychology and neuroscience contributed to



your understanding of pediatric rheumatology and patient care?

Studying psychology at university has had a broad impact on my life. It helps you start understanding how people think and why they make the decisions that they do. Good patient care and outcomes depend on so much more than medical knowledge. You can be an amazing diagnostician and know how to best treat a variety of conditions, but I think it has its limits if you aren't able to fully connect with your patients. Particularly, where I work, our patients and families often have many psychosocial stressors that complicate their care – from coming to appointments and taking their medication, among others. I think that all healthcare providers should have training in these “non-medical” aspects of care. It helps to build connections and trust and ensure that patients and families really believe in the treatments and changes you suggest for them.

If you had unlimited resources, what innovative project or research would you initiate to advance the field of pediatric rheumatology?

I would work with experts in medical education to develop teaching modules that cover the major pediatric rheumatic diseases and develop a curriculum that could be delivered to general practitioners/pediatricians/community health workers. Even in a huge city like New York, which is saturated with medical providers, we sometimes get referrals for children with pediatric rheumatic disease that were missed for a while and therefore come

to us very sick, often because the diseases are so rare and can have such varied presentations that they are not recognized by other providers. This probably happens even more in areas where pediatric rheumatologists are not available. There are probably so many children around the world who have an undiagnosed rheumatic disease that suffer unnecessarily and have preventable complications and may even lose their lives. While building the pediatric rheumatology workforce is an important long-term goal, I think that if we could at least make general practitioners (even in remote areas) aware of our diseases and show them basic initial workup and management, it would improve our recognition of disease.

Who has been the most influential mentor in your career, and what is the most valuable lesson they taught you?

My four attendings at my fellowship program at The Children's Hospital at Montefiore (Dawn Wahezi, Natalia Vasquez, Tamar Rubinstein, and Tamar Tanner) have collectively been my biggest and most supportive mentors who have really shaped my career. They are four passionate, brilliant, and determined women who constantly fight to achieve the best for their patients. They modeled for me how to advocate for my patients, pursue my passions, and how to have fun while doing it. I could not have gotten through fellowship without them. They always believed in me and I strive to emulate parts of each of them as I develop as a pediatric rheumatologist.

How do you empower your patients and their families to participate actively in their healthcare journey?

I try to use motivational interviewing to understand where my patients and families are currently, what their goals are, and how to help them achieve them. When discussing areas for change and improvement, I try to ask them to come up with ideas rather than giving them suggestions. I also try to help them understand why we make the recommendations that we do and to understand the long-term implications of the disease and treatment. This way, they don't feel like they're simply doing things just because I suggest them and rather they understand why everything is important and how they can take control over managing the disease.

What do you believe will be the next breakthrough in pediatric rheumatology, and how can current practitioners take advantage of it?

I think this will take time to develop and may not be the immediate next breakthrough, but I am optimistic that we will develop biomarkers to help us predict which children can be tapered off medication. It is very difficult when children and caregivers are grappling with the diagnosis of a chronic disease with numerous medications with significant side effects – they almost always want to know when they can stop medications, often before even starting them. Currently, it feels like we're guessing when we provide them that estimate. It is also challenging when you attempt to taper a child's medication and then they flare and become

difficult to recapture. The ability to more precisely counsel families and determine who has a better likelihood of being able to come off medications could make a big impact on our patients and families.

What ethical challenges have you faced in your research, and how did you navigate them?

I have worked on several projects trying to better understand juvenile dermatomyositis in African countries with an amazing team of collaborators. One of my biggest challenges has been navigating my role on the team. I have taken on a leadership role in the project, but the patient population is not one that I directly care for. I have tried to be mindful of my role as an "outsider" by listening to my team members and understanding their perceived priorities and needs. I have been far from perfect in this process and sometimes have learned through making mistakes and hoping for grace and understanding with an assumption of good intentions. Another challenging area has been "ownership" of the data – I have never worked on an international project that involves collecting patient data and underestimated the ethical board approvals unique to each institution to ensure patient data is protected. Given that our project involved multiple sites, it was almost like doing multiple applications and approvals at once. One of the biggest lessons I learned was to take a step back, listen, and understand – to ask questions rather than come in with an agenda.

How have your multilingual abilities

enhanced your professional interactions and research collaborations?

Language is such a powerful tool in allowing you to connect with others. I think this connection transcends simple communication and the ability to understand the words someone else is saying. I think an unspoken, deeper understanding and connection is palpable when you can communicate in the same language. I remember being at the PAFLAR Congress this year in Tunis [Tunisia] and meeting local rheumatologists who were kind and welcoming. When I responded in French and saw their surprise, it felt like some deeper understanding and connection developed instantaneously. Language helps me feel like we have something important that we share and has always helped me feel connected to others.

Where do you see PAFLAR in 10 years, and what role do you envision for yourself in its evolution?

I am constantly impressed and awed by PAFLAR's vision and constant progression towards improving care for children with rheumatic diseases in Africa. I think one of the most impactful areas they are working on is improving the pediatric rheumatology workforce – whether through a dedicated African fellowship program and/or through increasing awareness that these diseases exist and how to diagnose and manage them among general practitioners and community healthcare workers. There are probably millions of undiagnosed children with

rheumatic diseases in Africa who are suffering unnecessarily. The diseases are rare and can be difficult to diagnose given how varied their presentations can be. Without exposure to these diseases, healthcare providers likely miss many of these children. PAFLAR has already done so much to increase education and awareness, such as through their monthly webinars, awareness events, and congresses. Given PAFLAR's visionary leaders and passionate and tireless members, I am confident that in 10 years, they will have expanded the workforce with the downstream effect of detecting more children with rheumatic diseases. I hope to continue to be a member of PAFLAR's Advocacy and Education committees to learn from and work with my PAFLAR colleagues to help them develop these programs and raise awareness globally.

How do you find inspiration and recharge your creativity outside of your medical career?

I love being on the go and outdoors. I recharge by going for long walks or bike rides around New York and trying to pay attention to and appreciate my surroundings. There is so much beauty around us but it's easy to miss if you don't try and pay attention to it. I also love traveling and exploring new places.

Dr. Angela Migowa Is Igniting Hope in Pediatric Rheumatology

Text by Anthony Kuria
anthony@custommediahouse.com

Among medical pioneers, Dr. Angela Migowa stands out as a vibrant thread, weaving together passion, dedication, and an unwavering commitment to the well-being of children with rheumatic diseases. From Nyanza to the global stage, her journey in pediatric rheumatology is a testament to the power of one person's vision and determination. Through her groundbreaking work with the Pediatric Society of the African League Against Rheumatism (PAFLAR) and the establishment of the Hope Arthritis Foundation, Dr. Migowa has ignited hope for children and families affected by rheumatic diseases. This is the story of a trailblazer who's transforming lives, one patient at a time.

Dr. Angela Migowa wields a radiant smile that illuminates the lives of those around her with joy, hope, and optimism. The smile is not just a physical expression, it's a reflection of her soul, a window into the depths of her compassion and the vastness of her love for the children she serves. Her bubbly and affable personality gives the smile more credence.



Born in the village of Gwassi where Kenya, Tanzania, and Uganda converge on the shores of Lake Victoria, Dr. Migowa's story is that of a pioneer in the field of pediatric rheumatology.

"I grew up in Nairobi, attending Consolata Nursery and Primary School, then Kianda High School, and eventually medical school at the University of Nairobi."

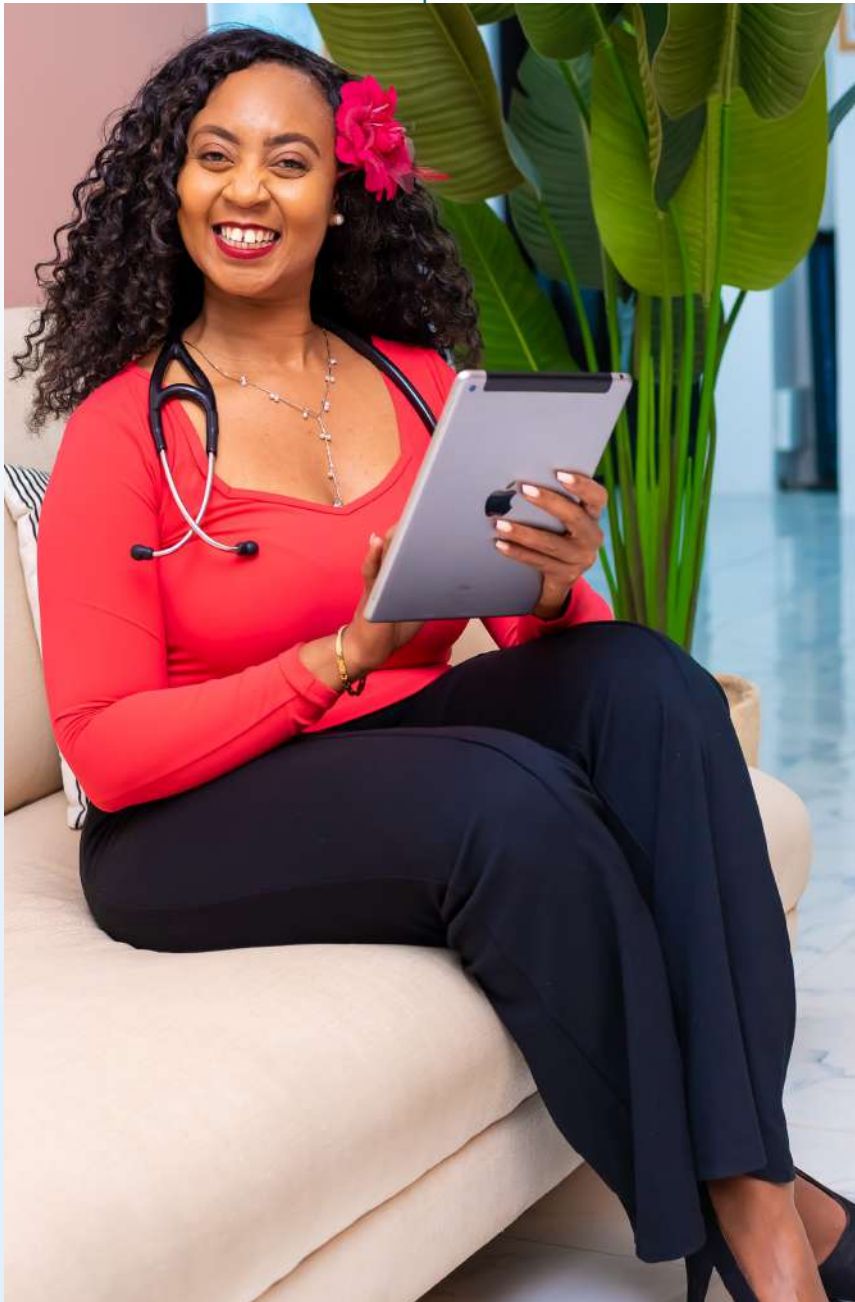
Her path to medicine was paved with a blend of personal experiences and an innate desire to heal. "My parents

tell me that from the age of nine, I would keep saying I will be a doctor," she recalls.

Her younger brother's battle with asthma, which saw him frequently hospitalized, further fueled her determination to pursue a career in medicine.

Dr. Migowa's journey took a pivotal turn during her Master's in Pediatrics at Aga Khan University when a 12-year-old girl with lupus passed away under her care.

"I was so demoralized and decided



then to study the field of medicine that cares for lupus patients. That is how I settled on pediatric rheumatology," she explains.

Destiny played its part when Dr. Migowa, 41, attended the African Rheumatology Scientific Congress, an event held in her home country, Kenya in 2009. While there, she met Dr. Ines Colmegna, an Argentinian

rheumatologist at Emory University, who would become a crucial mentor.

"She maintained email communication with me and eventually linked me up with my future supervisors at McGill University, who helped me apply for a Canadian scholarship to study rheumatology."

Her time at McGill University was transformative in terms of her medical education and the life lessons she learned.

"It was truly an exemplary model of mentorship and apprenticeship in medicine. The greatest lesson I learned from my Canadian family was 'Embracing every season of life.' The Canadians enjoy life irrespective of the season," she reflects.

Currently pursuing her PhD at the University of Ghent, Belgium, Dr. Migowa's research focuses on addressing diagnostic challenges for pediatric rheumatic diseases in Kenya.

"My PhD project constantly reminds me that research is about acknowledging we don't know it all but having the patience and perseverance to pursue the truth. I am always amazed at the patience and guidance of my supervisors, who often see what I haven't envisioned yet."

Professional Practice and Achievements

As the founding president of PAFLAR, Dr. Migowa and her peers have made significant strides in advancing the field of pediatric rheumatology in Africa since the organization was established in September 2019.

"During my fellowship, I attended several congresses, and often there would be no mention of Africa. This bothered me because I knew we had pediatric rheumatology patients but needed a systematic way of sharing our experiences."

Under her leadership, PAFLAR has achieved remarkable milestones, from establishing working groups and launching a Juvenile Idiopathic Arthritis (JIA) registry to conducting successful congresses.

Notably, Dr. Migowa joined her peers for the 2024 annual PAFLAR Congress in Tunis, Tunisia in May.

"It was a dream come true to see Africa unite in its mission to advocate for better care for children with arthritis in the continent. Above all, to see the zeal and passion of the participants and speakers from across the globe irrespective of our diverse backgrounds and cultures was gratifying. I am now convinced more than ever before that the mission shall continue and that is a legacy PAFLAR has established which is now undisputed. *Aluta Continua!*"

Challenges and Solutions

With only a few pediatric rheumatologists in Africa, Dr. Migowa

recognizes the challenges in increasing these numbers.

"Lack of dedicated time and financial resources, cultural perceptions, and balancing family, social, and professional obligations are major challenges," she notes.

She believes that creating more training opportunities within Africa, so that candidates do not have to leave their support networks, is essential to encouraging more healthcare professionals, especially women, to specialize in pediatric rheumatology.

A Balancing Act

Balancing her demanding professional life with personal commitments is a challenge Dr. Migowa navigates with grace and intentionality. "Self-care is so important. We cannot give what we do not have, so I purpose to rejuvenate myself and refill my cup of optimism, serenity, and energy," she emphasizes.

Dr. Migowa's routines include starting her morning with spiritual reading, reflection, prayer, and mass, followed by

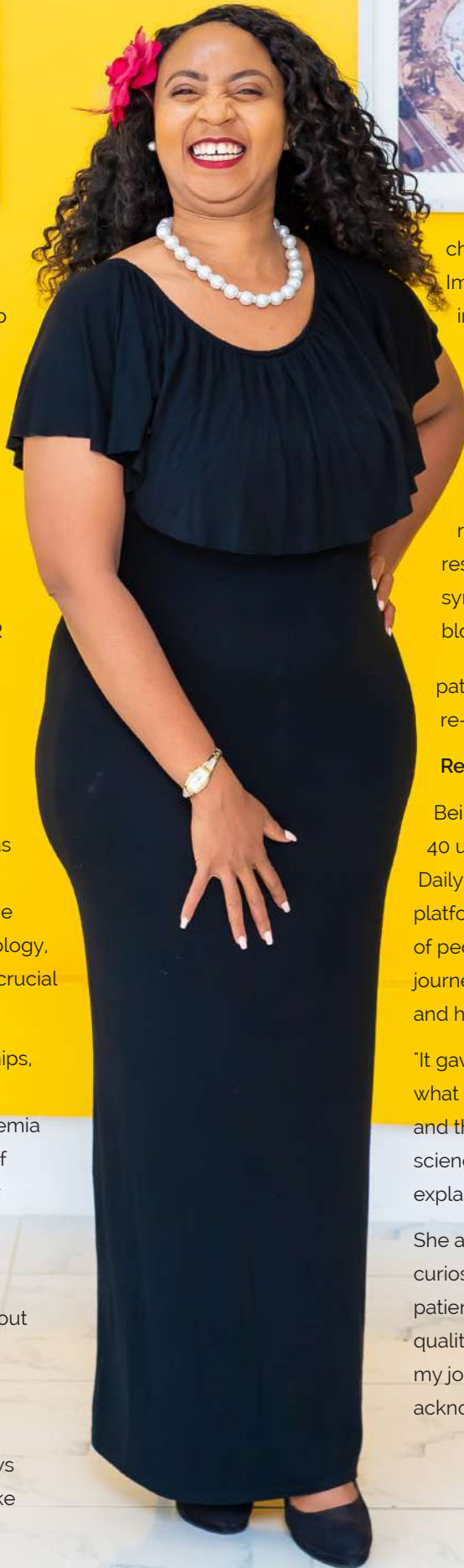
a visit to the gym before diving into her work. "I also enjoy reading non-medical books and dancing. Music serenades the soul, calms the mind, and energizes the heart," she adds.

Impact and Vision

Writer, Mark Twain said: "The two most important days in your life are the day you are born and the day you find out why." Dr. Migowa has already found out her 'Why'. "I want to build a fully equipped and staffed Center of Excellence for Pediatric Rheumatology Care."

Her vision is ambitious and inspiring and it has already started taking shape after she established the Hope Arthritis Foundation in July 2022. Since 2023, the Foundation has been training parents/caregivers/guardians, and healthcare workers to identify early signs of rheumatological diseases, and provide education and support to those affected by these conditions through masterclasses and boot camps.





"Knowledge is power. When guardians are empowered, they will know when to come forward for help and what should be done to help their children," she stresses.

Ever the optimist, Dr. Migowa foresees a future where the field of pediatric rheumatology in Africa will grow exponentially in the next five to 10 years. "Africa shall be the bedrock of innovation, the hub for human resources and skills. PAFLAR will be at the forefront of defining economic, research, and healthcare priorities for pediatric rheumatology patients," she says.

Her vision of exponential growth is buoyed by the collaborations she has had with international organizations that have put Kenya and Africa on the global agenda of pediatric rheumatology, and she sees these partnerships as crucial for advancing the field in Africa.

"Establishing collaborative partnerships, promoting inclusivity and equity in research, clinical practice, and academia is essential. Trust is the foundation of any successful relationship, whether professional or social," she affirms.

Innovations and Research

Dr. Migowa is particularly excited about innovations like therapeutic patient education, immune therapies, and immunometabolics.

"Therapeutic patient education allows patients to own their disease and take

charge of their management. Immune therapies and immunometabolics hold promise for targeted, precision medicine."

These advancements are changing the landscape of treatment for pediatric rheumatology. "Faster resolution and control of symptoms is possible. However, blocking specific immune pathways raises questions about the re-emergence of other pathways."

Recognitions

Being recognized as one of the Top 40 under 40 women by Business Daily Africa has given Dr. Migowa a platform to showcase the importance of pediatric rheumatology and the journey women in academia, science, and health go through.

"It gave me a platform to showcase what pediatric rheumatology is about and the journey women in academia, science, and health go through," she explains.

She attributes her success to her curiosity, focus, diligence, persistence, patience, and networking skills. "These qualities have been instrumental in my journey and achievements," she acknowledges.

The Transformative Role of Telemedicine in Pediatric Care

Text by Dr. Francis Fredrick



Telemedicine, defined as the use of electronic communications to exchange medical information to improve a patient's condition, has emerged as a revolutionary approach in healthcare. This technology encompasses a variety of devices and platforms that facilitate the exchange of information between patients and healthcare providers, and sometimes between two healthcare providers seeking opinions or support for patient care.

The rise in telemedicine utilization, particularly during the COVID-19 pandemic, highlighted its potential when patients were forced to consult their healthcare providers remotely due to restrictions. This

shift underscored telemedicine's capability to bridge the gap in care between regions with abundant medical expertise and those with limited resources. This is particularly relevant for pediatric musculoskeletal diseases in sub-Saharan Africa, a region burdened with a high number of affected children and a severe shortage of trained healthcare providers.

Africa is estimated to have the largest number of children with musculoskeletal diseases who are not accessing adequate care, with dedicated children's services available in less than 10 countries. Telemedicine stands out as a viable solution to support the care of

these children. By leveraging this technology, healthcare providers can remotely gather useful information to diagnose and manage diseases in affected children. The ability to obtain a patient's medical history clearly and directly, observe physical attributes such as skin, posture, and gait, and conduct consultations in real-time offers significant advantages.

However, telemedicine does have its limitations. While it allows healthcare providers to conduct thorough examinations, certain aspects, such as tactile assessments, are constrained without direct physical interaction. Additionally, managing patients with life-threatening conditions can be challenging through telemedicine alone.

There's also a risk that patients who are in remission and stable might become complacent, potentially avoiding necessary physical visits and compromising the timely identification of disease activity or complications that are not immediately apparent.

Despite these challenges, telemedicine offers numerous benefits beyond bridging the gap between regions. It promotes family-centered care, allowing patients to consult from home with the involvement of family members. This

mode of care delivery significantly reduces transportation costs, especially for stable patients who do not require frequent visits to healthcare facilities.

The implementation of telemedicine requires reliable internet access and the availability of electronic devices. Patients and families must be comfortable with exposing their living environments to healthcare providers, who might be considered strangers. Moreover, establishing a robust legal and policy framework is essential to ensure the proper provision and regulation of telemedicine services.

Enhancing Pediatric Care in Sub-Saharan Africa

The integration of telemedicine into pediatric care in sub-Saharan Africa has the potential to revolutionize the management of musculoskeletal diseases and other chronic conditions. Here are several ways in which telemedicine can enhance pediatric care in this region:

- 1. Increased Accessibility to Specialists:** Telemedicine can connect local healthcare providers with specialists in urban centers or even internationally. This access to specialized care can significantly improve the diagnosis and treatment of complex pediatric conditions.
- 2. Continuity of Care:** For children with chronic conditions, telemedicine provides a

platform for continuous monitoring and follow-up. Regular virtual check-ins can help manage conditions more effectively and reduce the frequency of hospital visits.

- 3. Education and Training:** Telemedicine can be used as a tool for educating and training local healthcare providers. Virtual training sessions and webinars can enhance the skills of healthcare workers in remote areas, improving the overall quality of care.
- 4. Emergency Consultations:** In emergency situations, telemedicine can facilitate rapid consultations with specialists, providing critical support to local healthcare providers and potentially saving lives.
- 5. Data Collection and Research:** Telemedicine platforms can facilitate the collection of health data, contributing to research and better understanding of pediatric diseases in the region. This data can inform public health strategies and policies.
- 6. Patient and Family Education:** Telemedicine can also be used to educate patients and their families about disease management, treatment adherence, and healthy lifestyle choices. This empowerment can lead to better health outcomes.

Overcoming Barriers to Telemedicine Implementation

While the benefits of telemedicine are clear, several barriers must be addressed to fully realize its potential in sub-Saharan Africa:

- » **Infrastructure Development:** Investment in internet infrastructure is crucial to ensure reliable connectivity in remote areas. Governments and private sectors must collaborate to expand internet access.
- » **Affordability of Devices:** Ensuring that electronic devices are affordable and accessible to all families is essential. Subsidies or programs that provide low-cost devices could be beneficial.
- » **Training Healthcare Providers:** Healthcare providers need training on how to effectively use telemedicine platforms and adapt their practices to remote consultations.
- » **Privacy and Security:** Ensuring the privacy and security of patient data is paramount. Implementing robust cybersecurity measures and educating patients about data protection is necessary.
- » **Policy and Regulation:** Governments need to develop comprehensive policies and regulations to govern telemedicine practices, ensuring quality care and addressing legal and ethical concerns.

4th PAFLAR Congress: A Celebrated Gathering in Tunisia

Text by Anthony Odallo

The 4th PAFLAR Congress was held in Tunis, Tunisia.



The 4th PAFLAR Congress, held at the Mövenpick Hotel Du Lac Tunis, was an immense success, gathering experts in pediatric rheumatology from across the globe. Organized in collaboration with LITAR (Tunisian League Against Rheumatism), and strengthened by the leadership of Prof. Wafa Hamdi, PAFLAR Treasurer, and Prof. Hela Sahli, President of LITAR, the congress took place under the theme: "Paediatric Rheumatology: Pioneering Early Diagnoses and Empowering the Future."

The congress featured numerous highlights, including the much-anticipated workshop on ultrasonography, led by internationally recognized experts Prof. Johannes Roth (Switzerland), Prof. Patricia Vega (USA), and Prof. Kawther Ben Abdelghani (Tunisia). Another standout was the continuation of the TPE workshop, acclaimed for its focus on patient-centered care. Sponsored by ILAR, this workshop, led by Drs. Kawther Ben Abdelghani, Hanene Ferjani, Alia Fazaa, Kawther Maatallah, Saoussen Miladi (Tunisia), and Mrs. Beatrice Fonjallaz (Switzerland), has gained international recognition for

its pivotal role in advancing medical practice.

The congress also included a workshop on challenging clinical cases, following the success of a previous PAFLAR CME event. The quality of discussions and the insightfulness of the content continued to impress attendees. Adding to the congress's prestige, the event received 7 CME accreditation points from INEAS, Tunisia's official accreditation organization, further underlining its professional relevance.

The event's hybrid format, managed impeccably by InfoPoint (Tunisia), allowed for seamless participation both in-person and online. This hybrid experience was complemented by significant media coverage, with Tunisian TV and radio stations providing extensive coverage, ensuring the congress's visibility to a broader audience.

Among the international attendees, Prof. Pui Lee from Boston Children's Hospital gave an insightful talk on DADA 2, while Prof. Rahma Guedri explored the fascinating role of Artificial Intelligence in medical practice. Additionally, Prof. Nuray

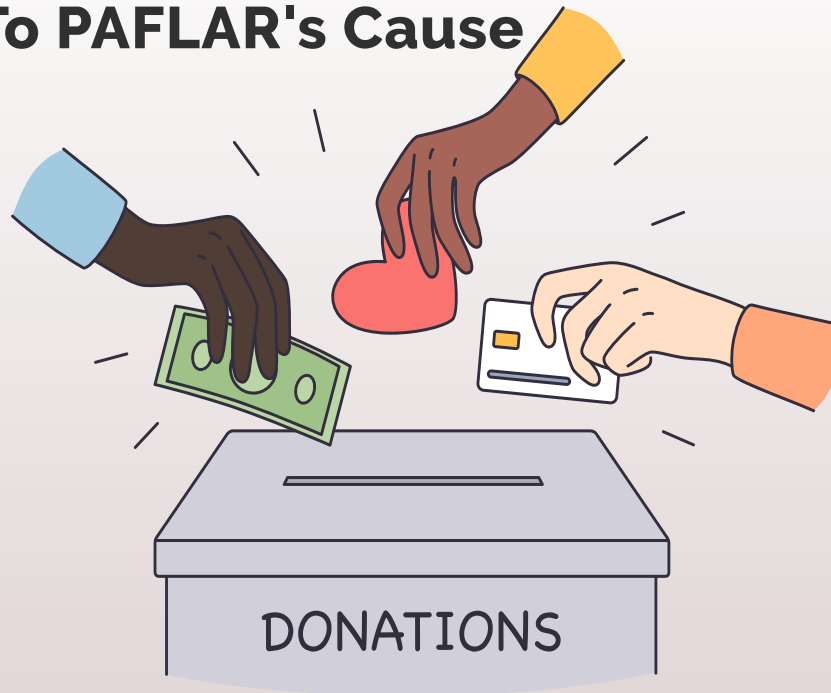
Aktay Ayaz from Turkey contributed valuable insights on pediatric rheumatology in Africa.

The congress also facilitated updates on groundbreaking African projects, including the Juvenile Idiopathic Arthritis (JIA) Management Guidelines and the JIA Registry, presented by Prof. Djohra Hadeef and Prof. Wafa Hamdi. These initiatives highlighted Africa's growing contributions to pediatric rheumatology. Representatives from Saudi Arabia and India further emphasized the global support for pediatric rheumatology in Africa.

This two-day event concluded with PAFLAR's Annual General Meeting (AGM), where discussions focused on sustaining and advancing PAFLAR's mission. The congress left attendees with a renewed sense of purpose and a commitment to future collaborations.

Special thanks go to all those who participated, including the many esteemed professors and experts from around the world. We also encourage everyone to visit our website to view the photos from the event, which have been expertly captured and shared by InfoPoint.

Donate To PAFLAR's Cause



Our Initiatives

Research Advancements

PAFLAR is dedicated to enhancing the understanding of rheumatic conditions in African children, striving for advancements in diagnostics and treatments to improve their quality of life.

Educational Programs

In our commitment to knowledge empowerment, PAFLAR provides healthcare professionals, parents and communities with valuable information on paediatric rheumatic conditions. Through our educational initiatives, we not only raise awareness but also play a pivotal role in enhancing early detection and timely intervention – essential elements in effectively managing these conditions. In 2023, our monthly Continuing Medical Education (CME) sessions, were attended by over 1100 participants

from 44 countries across the globe. These sessions featured seasoned practitioners delving into topics related to rheumatic conditions and fostering insightful discussions on challenging cases with healthcare workers. We are excited to note the positive growth trend, and we envision that this number will continue to expand in the future.

Groundbreaking Projects

PAFLAR leads groundbreaking initiatives to reshape the field of paediatric rheumatology in Africa. A significant milestone is the introduction of Africa's first guidelines for managing Juvenile Idiopathic Arthritis (JIA), offering healthcare practitioners a comprehensive framework for diagnosing and treating JIA in children. Furthermore, we are at the forefront of establishing Africa's first JIA registry, a crucial resource that will enhance our understanding of

the prevalence, demographics, and treatment outcomes of JIA in the region. This registry is intended to be a valuable tool for researchers, clinicians, and policy makers, promoting progress in this area.

PAFLAR recognizes the importance of Therapeutic Patient Education (TPE) in empowering patients and their guardians. Our groundbreaking TPE workshops have already been conducted in Tunisia and Kenya, equipping participants with valuable knowledge and skills to enhance their quality of life. As part of our patient-centered approach, these workshops serve to include patients and their guardians as stakeholders in the treatment process. Our goal is to extend these workshops to other countries, ensuring that children with JIA and their families throughout the continent can access the support and education they need.



PAFLAR

www.paflar.org