

PAFLAR NEWSLETTER

MAY - AUGUST 2024



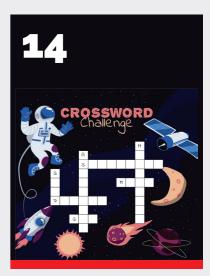












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PRESIDENT'S NOTE

Dear PAFLAR Community,

I am thrilled to extend a warm welcome to all of you as we embark on an exciting journey together in advancing pediatric rheumatology care across Africa. As we kick off the new PAFLAR Newsletter, I am honored to serve as the President of PAFLAR and look forward to collaborating with each of you to achieve our shared goals.

First and foremost, I would like to express my gratitude to our esteemed colleagues, Dr. Freddie Coker and Dr. Ayodele Faleye, for their outstanding contributions to the field of pediatric rheumatology. Their tireless efforts in raising awareness and sensitizing people about pediatric rheumatology have been truly commendable, and we are fortunate to have them as part of our community.

As we look ahead, I am delighted to announce the upcoming 2024 Congress in Tunis, Tunisia. This Congress promises to delve into primary and current topics in pediatric rheumatology, offering our community the opportunity to engage in networking, idea sharing

and fostering connections. We are honored to feature distinguished speakers and experts from around the globe, providing invaluable insights and expertise.

Our Therapeutic Patient Education (TPE) workshops, conducted in Kenya, Tunisia, and Nigeria in collaboration with the International League of Associations for Rheumatology (ILAR), were particularly successful. These workshops provided invaluable opportunities for learning and empowerment, and we are proud of the impact they have had on our community.

Looking forward, I am excited about the future editions of the PAFLAR Newsletter, which will play a crucial role in sensitizing people from all over the world about PAFLAR.

Together, we have the power to make a real difference in the lives of children and families affected by rheumatic diseases. I look forward to our continued collaboration and the remarkable progress we will achieve together.

The Path to Healing:

Dr. Ayodele Faleye's

Mission in Pediatric

Rheumatology

ew stories resonate as powerfully as that of Dr. Ayodele Faleye's quest to illuminate the path to healing for children living or diagnosed with rheumatic diseases. In a landscape where the illnesses are often misunderstood and misdiagnosed, she has emerged as a guiding light, a beacon of hope whose impact transcends mere diagnosis and treatment.

In the tapestry of pediatric healthcare across Nigeria, few threads shine as vibrantly as the work of Dr. Ayodele Faleye. As a pioneering force in pediatric rheumatology, she has dedicated herself to a mission that transcends diagnosis and treatment, weaving a narrative of hope, resilience, and transformative impact on young lives.

It was a calling ignited by the guidance of esteemed colleagues and an unwavering passion for patients grappling with rheumatic diseases. Too often, Dr. Faleye witnessed children suffering, their voices unheard, their struggles misunderstood or misdiagnosed as malaria, sepsis, or even spiritual afflictions. Determined to forge a new path, she embarked on a journey to revolutionize pediatric rheumatology care in Nigeria.

"My presence has increased awareness of pediatric rheumatic diseases among healthcare professionals, reducing diagnostic dilemmas and ensuring timely interventions," Dr. Faleye shares.

One poignant case that underscores the significance of her work is that of a 13-year-old girl with sickle cell anemia, whose recurrent anemia and numerous blood transfusions initially baffled specialists. It was Dr. Faleye's expertise that unveiled the true culprit – juvenile systemic lupus erythematosus (JSLE) – an entirely new experience for the medical team involved.

"She was first managed for hyperhaemolytic crisis, later autoimmune haemolytic anaemia before the rheumatology unit was invited. She was diagnosed with JSLE after our review and laboratory investigations. This was an entirely new experience for me and other specialists that were involved in her care," Dr. Faleye explains.

The many triumphs aside, the road to healing for her patients is often paved with challenges. Late presentations, financial constraints, and the unavailability of essential medications often impede progress. But, Dr. Faleye remains undeterred as she seizes every opportunity to raise awareness, dispelling myths and misconceptions that have long shrouded pediatric rheumatic diseases in Nigeria.

"One of the myths is that children

do not have chronic arthritis; it's been perceived as a disease of adults, especially elderly women," she explains. Through education and counseling, she debunks these fallacies, empowering families to embrace hope and adhere to treatment regimens.

For Dr. Faleye, caring for children with rheumatic diseases extends far beyond medical intervention. It is a holistic approach that considers their physical, emotional, and social well-being. "Caring for these children requires a multidisciplinary team," she emphasizes, "involving psychologists, occupational therapists, physiotherapists, pain therapists, social workers, and support groups to ensure their overall well-being."

One heartwarming story encapsulates the transformative power of Dr. Faleye's work. She recalls a 14-year-old girl, referred with a history of recurrent seizures and arthritis, whose journey seemed hopeless. Diagnosed with systemic lupus erythematosus, she embarked on a path of healing.

"After history, examination, and investigations, she was diagnosed with systemic lupus erythematosus, she improved greatly on medications. Now 19, she gained admission into a higher institution and transitioned to the adult clinic. She's now a happy young lady."

For parents, guardians, and caregivers embarking on the journey of supporting a child with rheumatic diseases, Dr. Faleye's guidance is invaluable.

"First is to counsel them about the specific disease, the aetiology, investigations, and management," she explains. "To tell them about the disease course, meaning of flares and complications." With compassion, she educates families

on the intricacies of their child's condition, from the root causes to the necessary tests and treatments.

Moreover, Dr. Faleye stresses the importance of the education on side effects of their medications and the need for regular clinical follow-up. "There's hope for these children if they adhere to their medications and attend follow-up clinics regularly."

Amidst the challenges. Nigeria has witnessed remarkable advancements in pediatric rheumatology care, heralding newfound hope for countless young lives. This is through the establishment of a pediatric rheumatology clinic in Lagos, with the presence of a dedicated pediatric rheumatologist. The rheumatologist has increased the suspicion of PRDs [Pediatric Rheumatic Diseasesl among healthcare workers and also reduced morbidity and mortality rate compared to the past." Furthermore, she highlights another significant breakthrough: "Availability of serology investigations and medications, especially biologics, though at a very high cost, is one of the significant improvements that have directly benefitted children with PRDs in Nigeria."

When it comes to dietary guidance for her young patients, Dr. Faleve's approach is pragmatic yet holistic. "A balanced diet is recommended," she advises. "High carbohydrate diets, sweets, and saturated fats should be restricted." She also underscores the benefits of certain foods, noting, "No diet can cause or cure PRDs, but fish can be taken frequently as it contains Omega 3 fatty acids which have an anti-inflammatory effect and it can also prevent cardiac complications." Through these recommendations, Dr. Faleye aims to support her patients' overall wellbeing, complementing their medical

care with a mindful, integrative approach to nutrition.

Dr. Faleye's affiliation with the Paediatric Society of the African League Against Rheumatism (PAFLAR) has been of great benefit. Through this partnership, she has found a platform for advocacy, education, and collaboration, uniting with like-minded professionals across Africa to elevate standards of care for children with rheumatic diseases.

"PAFLAR serves as a beacon of hope, fostering partnerships and initiatives that transcend borders, ensuring no child is left behind," Dr. Faleye asserts. Together, they champion the cause, igniting hope and transforming lives throughout the continent.

Looking ahead, Dr. Faleye envisions a future where every African child has access to high-quality rheumatology care and treatment, fueled by a robust network of trained pediatric rheumatologists, dedicated centers of excellence, and affordable access to essential diagnostics and medications.

"I believe there is hope for pediatric rheumatology in Africa," she declares. "With PAFLAR leading the charge, driving awareness, fostering collaboration, and spearheading initiatives, we can overcome barriers, bridge gaps, and pave the way toward a future where no child's health is compromised by rheumatic diseases."

In the heart of this visionary lies an unshakable truth – that every child deserves a chance at life, and every diagnosis a ray of hope. Through her steadfast commitment and partnership with PAFLAR, Dr. Ayodele Faleye is leaving an indelible mark on the landscape of pediatric rheumatology care in Africa.

Highlights from Our 2023 Hybrid Congress

he 2023 Congress garnered acclaim within the medical community as the first hybrid Congress, following two virtual editions due to the COVID-19 pandemic. This hybrid format united healthcare professionals and stakeholders in pediatric rheumatology worldwide. Themed, "Paediatric Rheumatology in Africa: Tackling Emerging Challenges", the Congress addressed several emerging dynamics within the field of pediatric rheumatology such as recent innovations, the use of social media in pediatric rheumatology, patient support groups, and patient-centered care, and multi-disciplinary care in pediatric rheumatology.

The success of the Congress gave PAFLAR a strong foundation to build upon for future Congresses.

The Congress commenced with a session on Therapeutic Patient Education (TPE), led by Dr. Wafa Hamdi and Dr. Kawther Ben Abdelghani. 12 participants, predominantly young doctors, engaged in interactive sessions that saw the team split into groups to answer questions and/or come up with scenarios to explain the importance of TPE in paediatric rheumatology.

Following the conclusion of the session, a WhatsApp group was formed and further lessons were given virtually on later dates. This culminated in the TPE workshops

that were held in Kenya, Nigeria, and Tunisia.

Standout Moments From The Congress

1. Researchers and clinicians delivered thought-provoking lectures on various subject matters. In line with PAFLAR's aim to uphold inclusivity, there were speakers from across Africa. Where there was a language barrier, live translation services were used. In the end, a lot of insight was offered due to the lectures being delivered by experts in their respective



fields. Feedback from participants confirmed this, as they commended how knowledgeable the speakers were in their fields. Each lecture was followed by a question-and-answer session (both virtual and physical), which often resulted in additional ideas discussed by the plenary. There were 35 lectures over the two days.

2. The Congress incorporated workshops that provided hands-on

learning experiences. The workshop topics included challenging clinical cases, infections and pediatric rheumatology, and Genetic/ Metabolic Diseases/other CTDs in Rheumatology. The main attraction of the workshops was musculoskeletal ultrasonography. PAFLAR partnered with Cincinnati Children's Hospital's Prof. Johannes Roth (Switzerland), and Dr. Kavulani Mutiso (Kenya). We also recognize Dr. Nasra who was able to mobilize volunteer children on short notice, to be subjects during the session. The efforts of the team ensured that an interactive and effective learning session was delivered. The machines in use were donated by Phillips and Mindray, further emphasizing the importance of collaboration.

3. A successful election process allowed PAFLAR members to select the leaders who will run the organization for the next two years. Four new board members joined the team, replacing the outgoing members who were thoroughly appreciated for their efforts. The incoming board members were recognized for their impressive efforts in PAFLAR's advocacy and in increasing the organization's visibility. The new membership was also equal in terms of gender, again, showing PAFLAR's commitment towards equality. The election also saw the president, vice-president, secretary, and treasurer retain their positions.

- 4.Exhibition booths outside of the plenary room ensured that our partner organizations were able to increase their visibility and possibly secure partnerships. Our booth was occupied by Tin Soldiers, an organization that supports people living with Fibrodysplasia Ossificans Progressiva (FOP). This also strengthened our relationship with Tin Soldiers and its affiliate organizations.
- 5. Researchers and clinicians from around the globe submitted abstracts of their latest studies, presenting their findings in the form of oral presentations and poster sessions. 75 abstracts were received and 73 were successfully published by Oxford. 30 of these abstracts were also presented

- as posters during the Congress.
 This dissemination of research
 broadened the knowledge base,
 encouraged constructive feedback,
 and inspired future investigations.
- **6.** Beyond the scientific sessions, the Congress offered networking opportunities. Attendees had the chance to connect with likeminded professionals, establish new collaborations, and strengthen existing partnerships.
- 7. The Congress solidified the spirit of Corporate Social Responsibility (CSR) by incorporating initiatives aimed at making a positive impact in society. This particular Congress featured two organizations: Clean Start and Rare Disorders Kenya. Clean Start's mission is to help reintegrate women, girls, and

- children impacted by the criminal justice system. Rare Disorders Kenya advocates for people living with rare diseases. These initiatives highlighted the commitment of PAFLAR and its members towards societal welfare.
- 8. The Congress witnessed significant participation and engagement. The pre-congress had 11 participants who all attended physically. On day one, 47 participants joined virtually while 32 attendees joined physically. Day two saw a reversal in attendance with 32 physical attendees and 47 virtual participants. 38 people attended the workshops on day two.





The Doctor Championing Pediatric Rheumatology in Sierra Leone

edicated pediatrician, Dr. Freddie Coker, is spearheading a transformative movement to revolutionize the landscape of pediatric rheumatology in Sierra Leone. From overcoming daunting obstacles to igniting a nationwide conversation on awareness and care through a media campaign, his journey is one of resilience, compassion, and unwavering commitment, as he tirelessly works to help address some of the gaps and challenges within Sierra Leone's health sector.

In the bustling city of Freetown, Sierra Leone, amidst the vibrant chaos of daily life, Dr. Freddie Coker stands as a beacon of hope for children battling rheumatologic conditions. With a fervent dedication to his cause, Dr. Coker, a seasoned pediatrician, has embarked on a mission to revolutionize the landscape of pediatric rheumatology in his homeland.

Born and raised in Freetown, Dr. Coker's journey into medicine was



fueled by a deep-seated passion to serve the most vulnerable members of his community—children. "I always knew I wanted to make a difference in the lives of children," Dr. Coker shares, reflecting on his formative years. "Medicine seemed like the most direct path to fulfilling that calling."

After completing his undergraduate medical education at the College of Medicine and Allied Health Sciences - University of Sierra Leone, Dr.

Coker pursued postgraduate training with the West African College of Physicians and the Ghana College of Physicians and Surgeons in Accra, Ghana. It was during his residency training that Dr. Coker first encountered the harsh realities faced by children with rheumatologic conditions.

"In the course of my practice, I encountered numerous children whose lives were profoundly impacted by rheumatologic conditions. Many had been misdiagnosed, their suffering prolonged by a lack of awareness and understanding of these complex illnesses."

Driven by a desire to effect change, Dr. Coker resolved to tackle the pervasive unawareness surrounding pediatric rheumatology in Sierra Leone.

Joining forces with like-minded colleagues, Dr. Coker found support in the Paediatric Society of the Africanan Af League Against Rheumatism (PAFLAR), an association of healthcare professionals, allied healthcare workers, patient support groups, and all relevant stakeholders involved in the care and management of Rheumatic and Musculoskeletal diseases afflicting the children of Africa, Rheumatic and Musculoskeletal diseases refer to a broad spectrum of disorders that affect the joints, muscles,

bones, and connective tissues in pediatric patients. These conditions can vary widely in severity and presentation, ranging from relatively mild and self-limiting to chronic and debilitating.

Some common rheumatic and musculoskeletal conditions in children include: Juvenile Idiopathic Arthritis, Juvenile Dermatomyositis, Juvenile Lupus, Juvenile Scleroderma, Juvenile Spondyloarthritis and Musculoskeletal Injuries.

"PAFLAR provided me with a platform—a community of passionate advocates who shared my vision," he explains. "Together, we could amplify our voices and effect real change."

However, the path ahead was not without obstacles. Dr. Coker recounts the initial struggles he faced in rallying support for his cause. "Securing resources, assembling a dedicated team, and reaching out to vulnerable communities were daunting tasks," he divulges. But he refused to be deterred

Through sheer perseverance and unwavering determination, Dr. Coker overcame these hurdles, laying the groundwork for a transformative movement. Under the banner of PAFLAR, he spearheaded a multifaceted campaign to raise awareness and educate healthcare professionals about pediatric rheumatology.

"Our efforts have been nothing short of remarkable," Dr. Coker remarks. "We've seen a surge in referrals for suspected rheumatologic cases, a testament to the growing awareness and recognition of these conditions."

Beyond his advocacy work with PAFLAR, Dr. Coker assumed leadership roles within the Sierra Leone Medical and Dental Association (SLMDA), leveraging his position to champion the cause c^c



pediatric rheumatology at a national level. As president of SLMDA, he now has a unique opportunity to influence policy and drive systemic change.

His dogged commitment is no surprise, considering the exceptional individuals he looks up to. "My mindset and journey have been influenced by individuals like Barrack Obama, the former US president who made me believe that no matter your background, you can achieve your dreams," says the 43-year-old.

He also mentions Tsatsu Tsikata, a Ghanaian lawyer, academician, and politician from whom he learned that the best way to succeed as a leader is to have a good team and believe in your team members.

"My mentor the late Prof. Ahmed Taqi, also inspired me to become a pediatrician. He was a consultant pediatrician and former principal of the College of Medicine and Allied Health Sciences in Sierra Leone. He always encouraged me to understand that hard work, determination, dedication, integrity, and empathy are key attributes to succeeding as a medical doctor. These have been key guiding principles for me throughout my journey," he adds.

Despite the demanding nature of his dual roles, Dr. Coker remains steadfast in his commitment to his patients and his cause. "Balancing the responsibilities of a pediatrician and SLMDA president is undoubtedly challenging," he acknowledges. "But with a supportive team and



unwavering determination, anything is possible."

According to Dr. Coker, he has on several occasions come across patients with suspected rheumatologic conditions. Unfortunately, a good number of these patients have been misdiagnosed. Based on this, it was evident that awareness and knowledge about pediatric rheumatology in Sierra Leone was poor, as it is in many other countries where pediatric rheumatology is an emerging area.

"I was therefore determined to make a difference in the level of awareness and knowledge about pediatric rheumatology in my country where we cannot boast of a single pediatric rheumatologist."

To remedy this, Dr. Coker and his team successfully ran a media campaign in observance of World Arthritis Day, 2023. At first, he struggled to get a platform and a clear vision as to how the campaign should look like. But, becoming a member of PAFLAR gave him a clearer picture of how he could embark on the campaign against pediatric rheumatism in Sierra Leone

"I shared this vision with colleagues, and a number of them were also enthusiastic about being part of the campaign. Thus, under the umbrella of PAFLAR, we planned activities including lectures, and radio and TV programs. The campaign was very impactful, as it attracted more healthcare professionals to become part of the movement against pediatric rheumatism. Moreover, we started receiving more referrals for suspected pediatric rheumatology conditions."

Looking to the future, Dr. Coker envisions a Sierra Leone where every child has access to quality rheumatologic care. "We have made significant strides, but there is still much work to be done," he reflects. "I am committed to expanding PAFLAR's reach, strengthening medical training programs, and advocating for greater resources and support."

Dr. Freddie Coker stands tall as a tireless advocate, resolutely transforming the landscape of pediatric rheumatology, one patient at a time.

PAFLAR's Therapeutic Patient Education Workshops Inspire Hope Across Africa



e got to witness the remarkable success of PAFLAR's Therapeutic Patient Education (TPE) workshops conducted in Kenya, Tunisia, and Nigeria, in collaboration with the International League of Associations for Rheumatology (II AR).

In Kenya, the Aga Khan University hosted the forum, where children and guardians were empowered through engaging educational exercises. Led by Dr. Angela Migowa and Dr. Musenya Mwangangi, the experts utilized interactive methods like flashcards and hoop games to get their messages across.

The Tunisian leg of our TPE workshops, led by seasoned doctors in the provision of patient education, received exceptional feedback. Dr. Wafa Hamdi spearheaded the effort, supported by Dr. Kawther, Dr. Alia, Dr. Hanene and Dr. Miladi. The Tunisian team has the most experience, having conducted dozens of these workshops.

In Nigeria, Dr. Ayodele Faleye's leadership resulted in a remarkable turnout, underscoring the potential for patient education and her inspiring commitment to a patient-centered approach. The TPE workshops have been empowering patients by imparting crucial knowledge about rheumatological conditions, treatments, and self-management, leading to improved health outcomes.

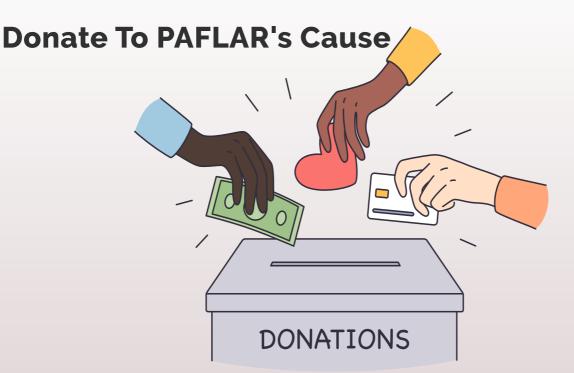
The workshops also serve as invaluable educational platforms for parents, caregivers, and guardians, fostering a collective understanding of patients' needs.

Although there have been challenges such as budget constraints and logistical issues in securing necessary materials and facilities, the workshops have been successful.

This success has been stemming from the use of child-friendly methods, games, and interactions, aligning with PAFLAR's renewed patient-centered focus in managing rheumatic diseases. Our gratitude extends to all partners, facilitators, and participants contributing to these empowering endeavors.

Your support is pivotal in advancing PAFLAR's mission to combat Juvenile idiopathic arthritis (JIA).

Join us in making a difference!



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.

Picture Speak

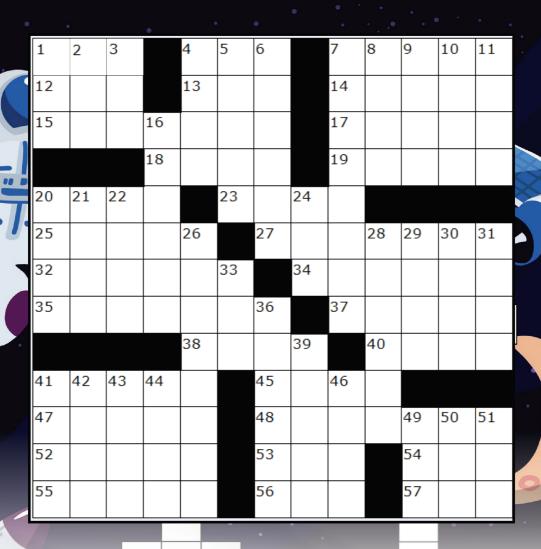








CROSS WORD



ACROSS

- 1. Drone
- 4. Pretend
- 7. Upper crust
- 12. Wind dir.
- 13. Sis's sib
- 14. Choir member
- 15. Childhood disease
- 17. Prickly plants
- 18. Positive votes
- 19. Delete
- 20. Ripened
- 23. Hide
- 25. Author Oscar
- 27. Teeter-totters
- 32. Burstyn and

- 34. Satiric
- 35. Defamation
- 37. Stadium
- 38. Was indebted to
- 40. Water vessel
- 41. printer
- 45. Animal docs
- 47. Diva's offerings
- 48. Bliss
- 52. Make cloth
- 53. Eminem's milieu
- 54. Green vegetable
- 55. Appointed
- 56. Raised railways
- 57. Male sheep

DOWN

- 1. Sewn edge
- 2. Take advantage of
- 3. "Oh, give home..." (2 wds.)
- 4. With competence
- 5. Crawl
- 6. Hurls
- 7. And so on (2 wds.)
- 8. Shakespearean king
- 9. Ancient Peruvian
- 10. Toddlers
- 11. Toledo's lake
- 16. Make unhappy
- 20. Astonishes
- 21. Fish feature
- 22. Vocalist Fitzgerald

- 26. Supported
- 28. Most tender
- 29. Over again
- 30. Merlot, e.g.
- 31. "The Lion King" villain
- 33. Make a seam
- 36. Worship
- 39. Sticker
- 41. Yard covering
- 42. Range
- 43. Thailand, formerly
- 44. Roof edge
- 46. Recipe abbr.
- 49. Rainy mo.