

NEWSLETTER

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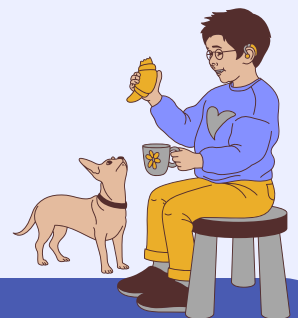
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MEET OUR BOARD

By: Tehreem Iman -&- Lubaina Ali

MEET OUR GENERAL SECRETARY:

DR. MARYAM FADHUL

Q: Could you please briefly define your role in AADMD?

“I am the General Secretary. I set goals, manage the resources, and coordinate the volunteers. I also work towards improving our programs and events.”

Q: What made you want to run for this position?

“I am among the oldest board members of the association. I have been working as an editor of AADMD for the past three years. I firmly believe in the importance of supporting people of determination. I witnessed the challenges faced by people of determination in their daily lives, which compelled me to make a positive impact and play a role in improving the lives of such individuals.”

Q: What are your plans for this year's AADMD volunteer activities?

“We are trying our best to involve and engage with the community in Sharjah, UAE. We are aiming to increase the number of our medical and dental visits. We plan to specifically cover the area near the University of Sharjah and host more events in that area. Therefore, we intend to increase the number of volunteers.”

Q: What skills do you find essential for executing your duties?

“In my opinion, the most crucial abilities are time management and volunteer relations. Planning and management are essential skills for my profession because I also have to organise events and programs.”

Q: What message would you wish to communicate with new members or those thinking about joining the organisation?

“For people considering joining the organisation, I would say that joining the association and dealing with people of determination is a great opportunity to make a positive impact and give back to society. This can be done by volunteering or simply by showing kindness towards people of determination. For people already part of the organisation, my message is do not underestimate the power of your actions to create a positive impact. Even with small actions, you can make a significant difference.”



Dr. Maryam Fadhul
GENERAL SECRETARY

Q: How do you see AADMD impacting the lives of people of determination?

“We work by empowering and engaging with our members. AADMD affects the lives of people of determination by educating and spreading awareness. This is done by organising lectures, online seminars, interviews, and visits to centres for people of determination.”

MEET THE DIRECTOR OF VOLUNTEERS: HEBA SAEED



Heba Talal Saeed
DIRECTOR OF VOLUNTEERS

Q: Can you briefly describe your role in AADMD?

“I am the Director of Volunteers at AADMD. For any event that we organise, I manage a checklist for the number of volunteers, delegate tasks between them, and ensure that every volunteer has something to do that benefits our society.”

Q: What were some of the things that made you want to run for this position?

“The main reason is that I am a people’s person; I love interacting and helping people. The other reason would be that I am very good at organising and managing people, which is primarily what this role asks of me. Further, I am also the bridge of communication between the student volunteers at AADMD and our President committee; something I thoroughly enjoy.”

Q: How will your membership in AADMD affect your future career?

“My membership in AADMD has helped me enhance my communication, organisation, management, and leadership skills. As an aspiring dentist, I hope to incorporate these skills into my practice in the future to form a trusting patient relationship and contribute to the growth of our healthcare system.”

Q: What are the most challenging aspects of your job in AADMD?

“My role at the AADMD is extremely rewarding because it gives me the opportunity to interact with student volunteers from not only UOS, but other universities in the UAE, helping me grow my social network. However, the most challenging aspect of my job would be to deal with ‘ghost-situations.’ Many times, the number of registered students does not tally with the actual number of student volunteers, and this is disappointing; however, to proceed with the event, we re-delegate tasks, and so far, all of our events have progressed smoothly.”

Q: How can AADMD broaden its societal impact?

“AADMD can broaden its societal impact by expanding its committee and collaborating with students not only in the UAE but also from other countries. If we can get more doctors, professors, and students on board, we will definitely be impacting more lives.”

Q: What message would you like to convey to new members or those wanting to join the AADMD?

“I 100% recommend it! Joining the AADMD will help you make better connections, evolve your personality, and enhance your communication and leadership skills. In addition, the feeling of giving back to society is extremely fulfilling and rewarding, so don’t hesitate!”

MEET OUR MEDIA DIRECTOR: REEM ALQASSIM

Q: Could you define your role in AADMD?

“I work as the media director of the American Academy of Developmental Medicine and Dentistry. I play a role mainly behind the scenes, such as editing and publishing content on the website. I have created content for social media and have edited interviews.”



Q: What are the objectives of AADMD for the year 2023-2024?

“Our goal for this year is to expand the AADMD community and increase our reach to as many people as possible. This can be achieved by creating content that is relevant and fresh so that AADMD can connect with more people.”

Q: What is your vision for AADMD?

“I want the organisation to be well-known and present everywhere. We wish to raise awareness about AADMD so that people get involved, volunteer, and contribute to bridging the gap between people of determination and society.”

Q: What motivated you to run for the position of a board member?

“When I first heard about AADMD, I was genuinely intrigued by the idea of bridging the gap between the people of determination and society. I also have relatives who are people of determination, so I have an idea of their struggles. I wanted to connect with more people and be part of an organisation that helped people of determination to live a fulfilling social life.”

Q: What message would you like to give to people already part of the AADMD and those who are planning to join the organisation?

“I want to thank everyone who has already joined AADMD for their efforts and contributions, and I want to encourage them to continue and give it their all. I also want to encourage anyone who is considering joining by saying that it is enjoyable, and you learn a lot by doing things that genuinely benefit others.”



Under The SPOTLIGHT

UNLOCKING THE SILENCE: EXPLORING THE BEAUTY OF SIGN LANGUAGE
WITH MS. LUBNA



By: Malak Bouali -&- Nada Nadima

In a world where communication knows no bounds, sign language stands as a testament to the power of expression beyond spoken words. Our interviewee, Ms. Lubna Al Maghaireh, is a certified sign language interpreter at the Disability Resource Center at the University of Sharjah. Join us as we delve into this interview with her and explore the mesmerizing world of sign language together.

Q: Could you please provide a brief explanation of sign language for those who might not be familiar with it?

“Sign language is a visual-gestural language used by deaf and hard of hearing individuals as well as providers in the deaf community to communicate. It relies on hand shapes, movements, facial expressions, and body language to convey meaning.”



Q: Can you share a glimpse about your journey and how you became interested in sign language and deaf culture? Were there any specific experiences or individuals who influenced your decision?

“In my case, growing up with deaf parents provided me with a unique perspective and exposure to sign language from an early age. Communicating with them using sign language was natural, and it fostered my curiosity about this visual-gestural form of communication.”

My parents' experiences and the challenges they faced while living in a world predominantly driven by sensory input also played a crucial role in my decision to delve deeper into deaf culture and sign language. Witnessing their resilience and their advocacy for deaf rights ignited my passion to contribute to the empowerment of the deaf community.



So, you could say that my parents' deafness was a significant factor that influenced my journey and sparked my interest in sign language and deaf culture.”

Q: What improvements or modifications do you believe are needed in sign language education programs?

“Sign language education programs can benefit from more widespread availability, standardized curriculum, and increased recognition as a legitimate language. It's also essential to involve deaf educators in program development.”



Q: As a sign language expert, what challenges did you face? how do you navigate these challenges while maintaining your passion and commitment?

“Challenges in this field can include breaking down communication barriers, advocating for deaf rights, and addressing misconceptions. I navigate these challenges by staying informed, fostering empathy, and collaborating with the deaf community.”



Q: Could you share a personal goal you have aspired to achieve related to your work with sign language and deaf culture?

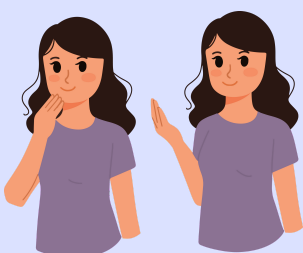
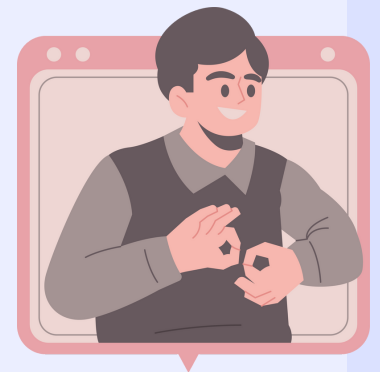
“One of my personal goals is to contribute to greater awareness and acceptance of sign languages worldwide, ensuring deaf individuals have equal access to education, employment, and services.”

Q: What's the most heartwarming experience you've had as a sign language expert: one where you felt a deep sense of impact on someone's life?

“One of the most heartwarming experiences was helping a deaf child express their thoughts and emotions for the first time through sign language. Witnessing their newfound ability to communicate was incredibly rewarding.”

Q: What advice would you give to someone who's interested in learning sign language?

“To someone interested in learning sign language, I would say: Start with a reputable course, immerse yourself in deaf culture, practice regularly, and be patient. Learning sign language is a valuable skill that promotes inclusivity and understanding.”



Q: Thank you so much for such a wonderful conversation. Is there anything you'd like us to conclude with?

“Thank you for the conversation! I would like to emphasize the importance of promoting deaf culture, advocating for accessibility, and supporting initiatives that empower the deaf community.”

SCIENCE SPEAKS

MEDICAL RESEARCH: FRAGILE X SYNDROME



By: Awab Musaad Suliman

INTRODUCTION

One genetic conundrum in the field of neurodevelopmental diseases that stands out for its intricacy and significance is **Fragile X Syndrome (FXS)**. The scientific community has been enthralled by this genetic condition for decades. It is characterized by a wide spectrum of cognitive, behavioural, and physical symptoms. Researchers are opening doors to understanding the larger landscape of brain functions as they delve further into its genetic complexities and unravel its influence on neurodevelopment.

HISTORY AND EPIDEMIOLOGY

In 1943, James Purdon Martin and Julia Bell reported case study of a family with intellectual disability affecting males more severely than females, where such pattern of inheritance was linked to chromosome X, where a gene called FMR1 was isolated. FMR1 is caused by a trinucleotide repetition leading to defect genetic makeup of Fragile X syndrome (FXS) otherwise known as Martin-Bell syndrome. FXS is an X-linked dominant disorder where features identified included language deficits, macroorchidism or enlarged testicles, seizures, and anxiety. In addition, individuals affected were more susceptible to disorders like autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). These symptoms are usually not apparent at birth, but they become clearer during the first year of life. The diagnosis is mostly made by the second or third year of life.



The prevalence of FXS varies between countries, but a systemic meta-analysis in 2014 revealed that it affects 1 in 5000-7000 men and 1 in 4000-6000 women worldwide. It is currently the second leading cause of intellectual disability (ID) (2.4% of all ID cases), trailing only Down syndrome.





EFFECT ON THE CAREGIVERS

The effects of Fragile X syndrome extend far beyond the lives of those bearing the condition. Families frequently traverse a maze of difficulties, from managing financial and emotional stress to getting specialised healthcare and education. Support groups and awareness campaigns turn into crucial lifelines that assist families in coping with the many demands that FXS places on them. A more understanding and informed environment for those who are afflicted is further facilitated by societal awareness and inclusion.

TREATMENT

There is currently no treatment for FXS because genetic modification, medical treatment, or medications have not been proven to fully undo the effects of the absence of FMR1 gene on foetal development. However, pharmacological treatment aims to improve behavioural symptoms linked to FXS. Antipsychotics, anxiolytics, sympatholytic, stimulants, and antidepressants are some of the most effective drugs prescribed for this purpose. Medications like Metformin, Sertraline, Minocycline and Lovastatin showed to help symptomatic relief like social deficits, repetitive behaviour and macroorchidism.



With the causative gene mutation identified, the revolutionary CRISPR/Cas9 system, which can inactivate parts of the DNA, was used to test deactivating the mutated FMR1 gene. Trials on mice brains showed that CRISPR/Cas9 was able to directly and effectively omit the mutated FMR1 gene.

CONCLUSION



Fragile X Syndrome is evidence of the complex interactions between genetics, neurodevelopment, and behaviour in people. Researchers have shed light on this condition and opened the door to deeper understandings of the wider spectrum of neurodevelopmental disorders by solving the genetic mystery underlying it. Advancements in research and therapeutic approaches hold the promise of enhancing the quality of life for individuals with Fragile

X Syndrome and providing support to their families. Such advancements also add to the knowledge needed to further understand the brain complexities and genetic configuration.



SCIENCE SPEAKS

DENTAL MANAGEMENT OF PATIENTS WITH HEARING IMPAIRMENT



By: Rand Alkhalidi

INTRODUCTION

Effective Communication at the dental office is essential for achieving successful treatments; however, communication for patients with hearing impairment can become a major barrier. These patients encounter difficulties communicating not only with the dentist but also with other staff at the dental clinic; thus, they are unable to make appointments or receive the help they need. Because of all these difficulties when approaching oral health providers, patients with hearing impairment can develop feelings of fear and anxiety which can cause them to avoid seeking dental care.



A lot of individuals within this community rely on sign language as their primary means of communication, thus they may not be able to engage in an active conversation with their clinician without the help of a sign language interpreter. And as most health care professionals lack any knowledge of sign language. It has been reported that for most patients with hearing impairment parents will act the interpreter for these patients instead of professionals. This can become quite uncomfortable for older patients as it compromises their privacy.

MANAGEMENT

Clear guidelines on the dental management of patients with hearing impairment are still lacking, however there are still a lot of things dentists and dental professionals can do to provide a more comfortable experience to these patients:



- A professional sign language interpreter must be provided at the dental office when needed to ensure effective communication.
- The use of visual mediums like charts and pre-recorded sign language videos were shown to be very effective, as patients with hearing impairment were shown to retain instructions given through visual mediums a lot better. (Figure 1)

- Appropriate training of dentists and health care professionals in general regarding hearing impairment awareness and management should be encouraged as this can eliminate these communication barriers.
- Some Studies have shown that removal of the mouth mask during treatments may improve communication with hearing-impaired patients.
- Multiple specialized health-care centers have been established across the world and have shown themselves to be very effective for deaf patients as these healthcare centers provide competent staff that are able to communicate with sign language and provide excellent care to these patients. So, if a nearby health center exists dentists should refer these patients to it.

Figure 1: Instructions to the hearing-impaired patient





SCIENCE SPEAKS

SPINAL MUSCULAR ATROPHY: ADVANCEMENTS IN MANAGEMENT



By: Habiba Mohamed

INTRODUCTION

Spinal Muscular Atrophy is a rare neuromuscular disorder caused by mutations in the Survival Motor Neuron 1 (SMN1) gene. The disease is characterized by selective loss of motor neurons, leading to progressive muscle atrophy and weakness. SMA has different types, with the most severe being SMA Type I, which often leads to death in early childhood.

TRADITIONAL APPROACHES

Historically, treatment for SMA has been largely supportive, focusing on symptom management and supportive care such as respiratory and nutritional support. Recent advancements have shifted the treatment paradigm of SMA. Gene therapy has emerged as a promising approach, primarily targeting the underlying genetic defects in SMA.

ZOLGENSMA: A PIONEER IN SMA TREATMENT

Based on the information provided by the FDA, Zolgensma (onasemnogene abeparvovec-xioi) stands out as the first gene therapy approved to treat children less than two years of age with SMA. This innovative therapy works by replacing the defective or missing SMN1 gene with a new copy. One-time intravenous infusion has shown substantial efficacy in clinical trials, resulting in prolonged survival, improved motor function, and the achievement of developmental milestones that are otherwise not attainable for these children.(4)



NUSINERSEN: A TARGETED APPROACH

Another pivotal therapy in the SMA landscape is Nusinersen (marketed as Spinraza). It does not replace the SMN1 gene but instead modulates the splicing of its homologous gene, SMN2, leading to an increase in the functional SMN protein, which is crucial for motor neuron survival.(1)(2)

CURRENT RECOMMENDATIONS AND PATIENT EDUCATION

As gene therapies continue to evolve, it is imperative to offer appropriate education to patients and their families. Organizations such as the American Society of Gene and Cell Therapy provide valuable resources detailing the nuances of SMA and the benefits and risks of therapies such as Zolgensma and Spinraza.(5)





FUN FACTS



HYDROCEPHALUS



By: Afrah Hajmydeen

The term **hydrocephalus** is derived from the Greek words "hydro" (water) and "cephalus" (head). Although the term translates as "water on the brain," it actually refers to the accumulation of cerebrospinal fluid in the ventricles of the brain.



One of the most prevalent birth anomalies, affecting **1 out of every 500** babies each year.



September is the hydrocephalus awareness month.



It is the most common cause for **brain surgery** in children.



Apart from the congenital cause, a study shows that 10% of **traumatic brain injury** cases result in hydrocephalus.



Shunts are devices used as a treatment by draining the excess fluid into other parts of the body through a long flexible, valve regulated wire connecting both spaces.

Death rates have dropped dramatically in the last 25 years, from **54% to 5%** due to advance treatment modalities.



Children with hydrocephalus may experience **learning difficulties, along with social and physical skills impairment.**



MYTH VS FACT

SPINAL MUSCULAR ATROPHY

By: Khadijah Zaidan

MYTH #1: ALL INDIVIDUALS WITH SMA HAVE THE SAME LEVEL OF DISABILITY.

Fact: There are several types of SMA, ranging from severe type 1 to milder type 4. The level of disability and the progression of the condition can vary significantly among individuals. Even individuals with the exact SMA type can have different symptoms. It is a misapprehension to assume anything about someone with SMA, based on someone else's experience.

MYTH #2: SMA IS A GENETIC DISEASE THAT OCCURS ONLY IN CONSANGUINEOUS MARRIAGES.

Fact: SMA is typically an autosomal recessive disorder, meaning that to get the disease, one must inherit two copies of the mutated gene (one from each parent). In fact, one in every 40-50 people globally are carriers of the gene that causes SMA, so consanguineous marriages can increase the probability of both parents carrying the same rare recessive gene mutation, but SMA can still arise in non-consanguineous marriages if both parents are carriers of the mutated gene.

MYTH #3: PEOPLE WITH SMA HAVE INTELLECTUAL AND SOCIAL DISABILITIES.

Fact: Like the public, people with SMA have a wide spectrum of academic, intellectual, and social abilities. This is mainly because SMA affects physical function and, in some individuals, speech, which may influence social interactions and daily activities. It is important to note that mental health issues such as anxiety and depression are generally higher in people with physical disabilities.



MYTH #4: SMA IS INCURABLE AND DOES NOT RESPOND TO TREATMENT.

Fact: In 2021, the FDA approved three medications that can help improve the quality of life of individuals with SMA by improving their motor and physical function. However, it is important to note that this treatment is not a cure, but it could benefit the patient significantly if it was started early. Consequently, the earlier the diagnosis, the earlier the treatment is administered, and the better the outcomes. Pharmacotherapy alone was never the solution for people with SMA; it was always adjacent to other forms of care, such as respiratory support, assistive devices, and physiotherapy.

MYTH #5: SPINAL MUSCULAR ATROPHY IS A RARE CONDITION

Fact: SMA is more common than once believed, as it affects approximately one in every 10,000 births worldwide, despite all backgrounds and ethnicities.

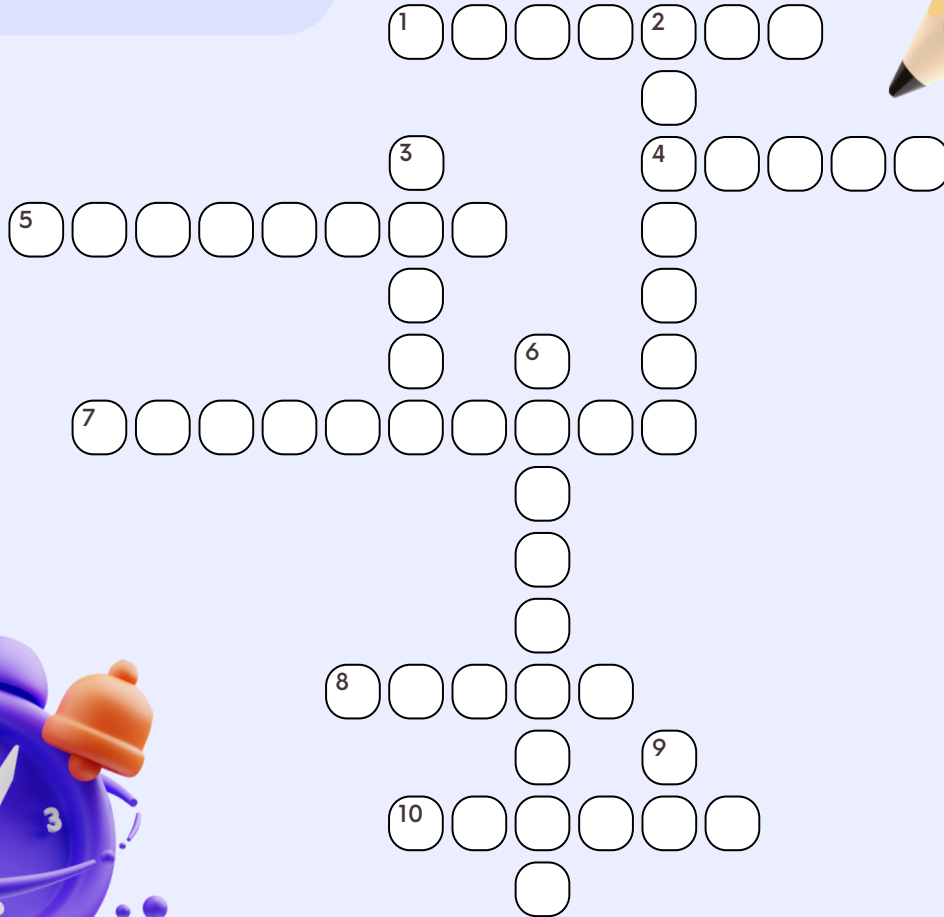


The Arcade: CROSSWORDS

ALZHEIMER'S DISEASE



By: Jana Elshafei



ACROSS

1. a sign on radiology modalities affecting cerebrum
4. one risk factor of Alzheimer's
5. impaired ability to remember, think, or make decisions that interferes with everyday activities
7. most common progressive sign of Alzheimer's
8. number of stages of Alzheimer's
10. twisted fibers of another damaging protein called tau that build up inside cells

DOWN

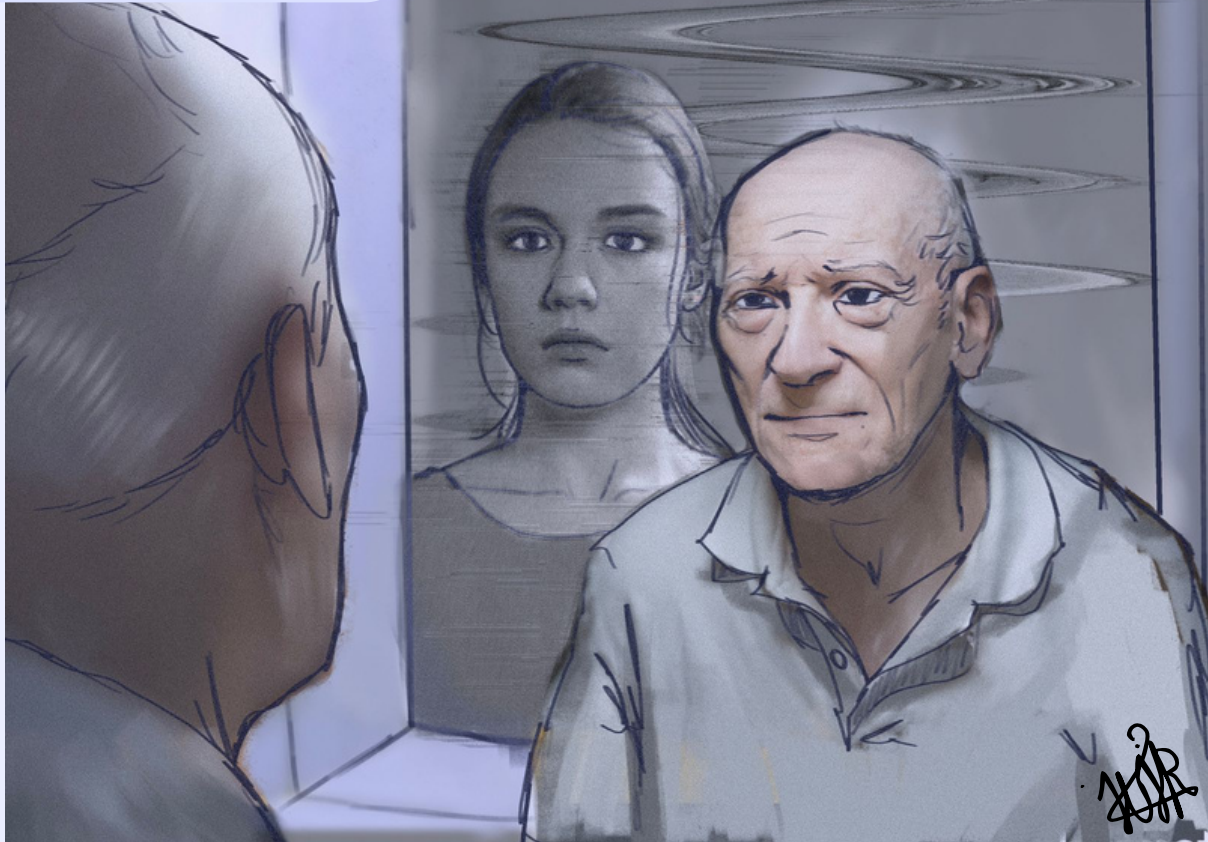
2. damaging deposits of a protein fragment called beta-amyloid building up in spaces between nerve cell
3. the most common age for diagnosis
6. a Cholinesterase inhibitor drug approved for delaying disease
9. a radiology modality most commonly used for investigation of Alzheimer's

Out Of Mind



By: Mohamad Assker

prologue



*In twilight's embrace, a poignant scene,
A story emerges, where memories convene,
Not himself, but a soul in decline,
In the shadows of time, some tales intertwine.*

*Deja vu's tease, and moments sway,
A caregiver's solace, a daughter's display,
In quiet questions, secrets unfurl,
In forgotten fragments, emotions whirl.*

*"Are you my daughter?" he tenderly inquires,
In the depths of his eyes, a longing transpires,
Our narrative commences, where memories blend,
In "Out Of Mind," a journey to transcend.*



Out Of Mind

poem

★ By: Hind Al Khalaf

*I wrote it somewhere where's its hard for me to see
My own book, a story of my life somewhat like a biography
Falling down the hourglass my memories have faded
A beautiful feeling it was as if it was painted*

*Though I cannot grasp what is it that I search for
Something I had, a long long time ago
If only I could remember those blurry views
I'm having all kind of Deja Vus*

*Life is black and white and filled with blues
yet I can't find myself to remember
That one night in June
A face so familiar and as bright as the moon
A voice as beautiful as a classical tune*

*Who are you dear? I asked her patiently
She looked at me with a smile and laughed painfully
" Do you remember me ?"
As She looked at me with tears in her eyes
Isn't she just my caregiver ? I wonder why?*

*She wrapped her arms around me and showered me with tears
I felt terrible as if I was thrown on millions of spears
I held her tightly as she sang a beautiful tune
The same tune the time I lost my daughter that one night in June..*

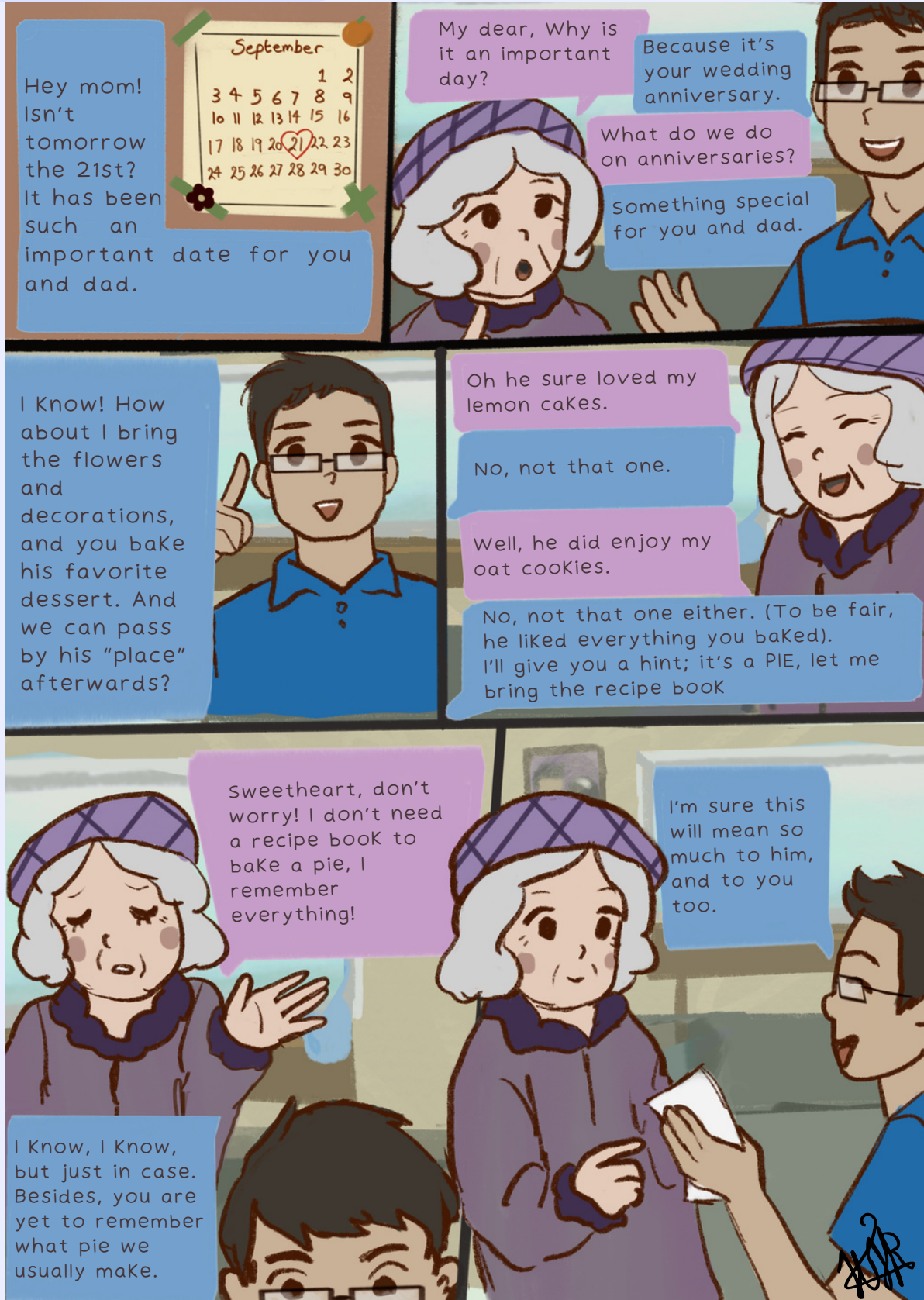
*I held her hand and sang along with her
Is it time for me to end my chapter as a litterateur?..*

*After crossing the oceans and stepping with the wounds on saltwater..
I asked her one question...
" Are you my daughter ? .."*

COMIC STRIP

THE "BIRTHDAY" – ALZHEIMER'S DISEASE AWARENESS

By: Hajir Saeed



COMIC STRIP

THE "BIRTHDAY" — ALZHEIMER'S DISEASE AWARENESS



By: Hajir Saeed



COMIC STRIP

"NIGHT SHIFT" : EXTRA

By: Hajir Saeed



APPENDIX

The Arcade- Crosswords Answer Key

- | | |
|--------------|---------------|
| 1. Atrophy | 6. Donepezil |
| 2. Plaques | 7. Memoryloss |
| 3. Sixtyfive | 8. Seven |
| 4. Aging | 9. CT |
| 5. Dementia | 10. Twists |

Medical Research

- Elhawary, N. A., AlJahdali, I. A., Abumansour, I. S., Azher, Z. A., Falemban, A. H., Madani, W. M., Alosaimi, W., Alghamdi, G., & Sindi, I. A. (2023). Phenotypic variability to medication management: An update on Fragile X syndrome. *Human Genomics*, 17(1). <https://doi.org/10.1186/s40246-023-00507-2>
- Milla, L. A., Corral, L., Rivera, J., Zuñiga, N., Pino, G., Nunez-Parra, A., & Cea-Del Rio, C. A. (2023). Neurodevelopment and early pharmacological interventions in Fragile X syndrome. *Frontiers in Neuroscience*, 17. <https://doi.org/10.3389/fnins.2023.1213410>
- Liu, X. S., Wu, H., Krzisch, M., Wu, X., Graef, J., Muffat, J., Hnisz, D., Li, C. H., Yuan, B., Xu, C., Li, Y., Vershkov, D., Cacace, A., Young, R. A., & Jaenisch, R. (2018). Rescue of fragile X syndrome neurons by DNA methylation editing of the FMR1 gene. *Cell*, 172(5). <https://doi.org/10.1016/j.cell.2018.01.012>
- Hunter, J., Rivero-Arias, O., Angelov, A., Kim, E., Fotheringham, I., & Leal, J. (2014). Epidemiology of Fragile X Syndrome: A systematic review and meta-analysis. *American Journal of Medical Genetics Part A*, 164(7), 1648–1658. <https://doi.org/10.1002/ajmg.a.36511>

Dental Research

- Campos, V., Cartes-Velásquez, R., & McKee, M. (2020). Oral health and dental care in deaf and Hard of hearing population: A scoping Review. *Oral Health & Preventive Dentistry*, 18(3), 417–425. https://doi.org/10.3290/j_ohpd.a44687
- Gupta, L., Jain, P., Mora, L. N., & Mujho, T. (2018). Evaluation of different visual method used, to enhance communication skills between dental care providers and speech and hearing impaired patients. *Indian Journal of Dental Research*, 29(4), 418. https://doi.org/10.4103/ijdr.ijdr_741_16
- Schniedewind, E., Lindsay, R., & Snow, S. G. (2021). Comparison of access to primary care medical and dental appointments between simulated patients who were deaf and patients who could hear. *JAMA Network Open*, 4(1), e2032207. <https://doi.org/10.1001/jamanetworkopen.2020.32207>

Pharmacological Research:

- Finkel, R. S., Mercuri, E., Darras, B. T., et al. (2017). Nusinersen versus Sham Control in Infantile-Onset Spinal Muscular Atrophy. *New England Journal of Medicine*. <https://www.nejm.org/doi/10.1056/NEJMoa1706198>
- Wurster, C. D., & Ludolph, A. C. (2021). Nusinersen for spinal muscular atrophy. *Cochrane Database of Systematic Reviews*. <https://pubmed.ncbi.nlm.nih.gov/33743238/>
- Lefebvre, S., Bürglen, L., Reboullet, S., et al. (1995). Identification and characterization of a spinal muscular atrophy-determining gene. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10104684/>
- FDA Press Announcement. (2019). FDA approves innovative gene therapy to treat pediatric patients with spinal muscular atrophy, a rare disease and leading genetic cause of infant mortality. <https://www.fda.gov/news-events/press-announcements/fda-approves-innovative-gene-therapy-treat-pediatric-patients-spinal-muscular-atrophy-rare-disease>
- American Society of Gene & Cell Therapy. (n.d.). Spinal Muscular Atrophy Disease & Treatments. <https://patienteducation.asgct.org/disease-treatments/sma>

Myth Vs. Fact

- Keinath MC, Prior DE, Prior TW. Spinal Muscular Atrophy: Mutations, Testing, and Clinical Relevance. *Appl Clin Genet*. 2021 Jan 25;14:11-25. doi: 10.2147/TACG.S239603
- Mazzone ES, et al. Revised upper limb module for spinal muscular atrophy: Development of a new module. *Muscle Nerve*. 2017 Jun;55(6):869-874. doi: 10.1002/mus.25430. Epub 2017 Feb 6
- Belter L, Cook SF, Crawford TO, et al. An overview of the Cure SMA membership database: Highlights of key demographic and clinical characteristics of SMA members. *Journal of Neuromuscular Diseases*. 2018; 5(2): p.167-176. Doi
- Prior TW, Nagan N, Sugarman EA, Batish SD, Braastad C. Technical standards and guidelines for spinal muscular atrophy testing. *Genet Med*. 2011; 13(7): p.686-694. doi:

Fun Facts

- Shuer, L. (n.d.). *Hydrocephalus – Causes, Symptom and Surgical Treatments*. AANS. Retrieved August 9, 2023, from <https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Hydrocephalus>
- Deng, H., Goldschmidt, E., Nwachuku, E., Yue, J. K., Angriman, F., Wei, Z., Agarwal, N., Puccio, A. M., & Okonkwo, D. O. (2021). Hydrocephalus and Cerebrospinal Fluid Analysis Following Severe Traumatic Brain Injury: Evaluation of a Prospective Cohort. *Neurology international*, 13(4), 527–534. <https://doi.org/10.3390/neurolint13040052>
- Hydrocephalus Facts*. (2022). Hydrocephalus Hope, Inc. Retrieved August 9, 2023, from <https://hydrocephalushope.org/hydrocephalus-facts>
- September Is Hydrocephalus Awareness Month: What You Need to Know*. (2021, September 28). Advanced Neurosurgery Associates. Retrieved August 9, 2023, from <https://ana-neurosurgery.com/september-hydrocephalus-awareness-month/>