

## President's message

We just completed World Alzheimer's month (WAM) in September. It brought to culmination a concerted effort across the globe on 'Know Dementia, Know Alzheimer's. Together we can do so much!'.

It was a busy month for us at the LAF. Our campaign kicked off with the Virtual Walk from Ratnapura to Independence square, Colombo. Our social media messages, press articles, tv and radio interviews, clips and jingles were rolled out continuously on various aspects of dementia, its care, and the lived experience of persons with dementia and their carers. We are grateful to all the media organisations who supported us including our sponsors – Wijeya Newspapers, Hi-online, MTV and Legends. We also thank our generous donors who supported the cause. We had a physical walk after a lapse of two years, from independence square to our activity and resource centre at Maradana. You will find more information on our activities in this newsletter.



We have been able to resume our regular activities including the activity centre and memory screening assessments over the past few months. The client numbers are slowly picking up and the volunteers are overjoyed that they can spend time productively with them. Music, singing and dancing is in the air as the year approaches to an end.

Our AGM was on the 28<sup>th</sup> and we were happy to welcome Nimal Gunewardena to the Board of Directors. He brings in a wealth of experience from his illustrious career at the helm of a advertising cum public relations firm. We were sad that Ren Lan Mather stepped down as a custodian this year but are grateful for her commitment and service to LAF over the years. We were happy though that we found a trustworthy custodian in Shewantha Rodrigo who willingly steps in to take her place. We reiterate that all our leadership positions are entirely voluntary in nature with no remuneration whatsoever. It is the same with all the others who conduct the activity center for our clients.

I am hopeful that the volunteerism we embrace at LAF initiated by Lorraine Yu will continue to enrich our mission and help us to deliver our service efficiently with minimum overheads despite the financial challenges we face as a nation.

**Prof Shehan Williams**

**President**

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## Free Memory Screening

**2022**

Oct - 7th 21st

Nov - 4th 18th

Dec - 2nd 16th

**Appointments are limited.**

**Please call the Helpline 2667080**

**to register.**



## Memorable Steps 2022 - A Virtual Walk for Alzheimer's

### 67.9 Million steps for Alzheimer's

Proving that together we can do so much, 641 individuals and 23 Teams registered for what has become an annual virtual walk to mark World Alzheimer's month. On 21<sup>st</sup> September, a total of 67.9 million steps had been logged in. The walk was organized in partnership with the team from Auyobo.life to encourage physical and mental exercise, one of the key factors in helping to delay or prevent Alzheimer's disease and vascular dementia, while educating participants about the disease. The virtual walk from 1<sup>st</sup> to 21<sup>st</sup> September covered a distance of 115,500 steps from Ratnapura to Independence Square in Colombo.

The number of participants increased significantly from the previous year, which is most heartening, and we hope it sets the precedent for more people to be physically active and live healthier lifestyles. A symbolic walk from Independence Square to LAF office was held on Saturday, 24<sup>th</sup> September which culminated with the presentation of awards to the winners of the Corporate Challenge and the individual categories. The occasion was also used to distribute information to passersby. Subsequently a raffle draw was also conducted for those who completed the walk on time and 21 winners were selected.

We thank all the walkers, whether you completed it or not. Your support was a huge encouragement to us and we trust an inspiration to keep being active. We look forward to having you join us again next year along with all those who were unable to make it this time around.

As always, this would not have been possible without the support of our sponsors, Sun Pharmaceuticals Industries (Pvt) Ltd, ADZ Insurance Brokers (Pvt) Ltd, Janashakthi Life and First Capital, Kalbe International Sri Lanka and our volunteers, who continue to silently carry out yeoman service. Our sincere and heartfelt thanks to all of you and our staff at LAF – without you nothing would be possible.

This year saw significant media support and interest: our thanks to Dentsu Grants for their visuals, Capital Maharaja group for their Radio and TV sponsorship, and to Rishini Weeraratne and her team from Daily Mirror online for several interviews and videos that were publicized. If anyone would like to watch or shares these informative interviews, please visit our Facebook page or our website [www.alzlanka.org](http://www.alzlanka.org).

To create awareness about Alzheimer's and the support offered by LAF, both traditional media and social media were leveraged, and the press release was covered in Sinhala and English. Twenty thousand SMS were also sent out to recipients in the greater Colombo area, highlighting Alzheimer's as not being a normal part of aging, and directing those who required more information to our website. An email on the Virtual Walk covering both the individual and Team challenge was also circulated to 5,000 individuals by MIS Holdings. In addition to the information regarding the walk our FB page used the Infographic designed by Alzheimer's Disease International (ADI) in Sinhala, Tamil and English, to drive home the 12 main risk factors.

Despite the overall Country situation and uncertainty, many activities were conducted to draw attention to the issue and create awareness. We hope to continue such activities throughout the rest of the year as well and not just limit it to the month of September.

By - Romany Parakrama



**CALL OUR HELP LINE**

**2667080**

**Monday to Friday | 9am– 5pm**

**For information on dementia and dementia care management**



(Contd)

# Memorable Steps 2022 - A Walk for Alzheimer's



## Virtual Walk 2022 - CONGRATULATIONS to all the winners



**TEAM CHALLENGE WALK**

**Winners - BIG FOOTERS**  
David Peiris Holdings Pvt Ltd



**R/Up - WHITE WALKERS**  
Morison Pvt Ltd



**INDIVIDUAL WALK**

**1st - Amandi Bambarenda**



**2nd - Nadun Kodikara**  
**3rd - Anton David**

**MEMORABLE STEPS 2022 VIRTUAL WALK**

**ayubalife**  
LIVE HAPPY

**CONGRATULATIONS!**  
RAFFLE DRAW WINNERS

CHAMINDA BANDARANAYAKE	GAYAN HASARANGA
NIRUSHA NAGULESWARAN	THILINI PERERA
CHINTHAKA LOKULIYANA	SHARBA NANTHA
SANDUNI ARIYADASA	DULIN RAJAPAKSE
CHARITHRI DENAGAMAGE	USHARA PASINDU
VENURI RUHUNAGE	DIHAN JAVARATNA
SARINI JAYAWARDHANA	PRASAD AMARAKOON
SUJITH CHAMINDA	LAKMAL MUNASINGHE
POORNIKA HARSHANI	AJANTH SANAA
KURUPARAN THENUKANAN	KASUN CHAMARA
THILEKSANA SIVANANTHAN	

#MEMORABLESTEPS2022

## Thank You to our Sponsors



**Sun Pharmaceuticals**



**ADZ Insurance Brokers**



**Janashakthi Life**



**First Capital**

## *World Alzheimer's Report 2022*

**As many as 85% of people with dementia could be missing out on post-diagnosis care**

**On September 21, 2022 Alzheimer's Disease International (ADI), the international federation of 105 Alzheimer and dementia associations around the world released the *World Alzheimer's Report 2022 – Life after diagnosis: Navigating treatment, care and support*, which was co-authored by McGill University.**

The report focuses on the urgent need for significant improvements to essential post-diagnosis treatment, care and support services for the over 55 million people living with dementia across the globe and robust plans to support the forecast 139 million people by 2050.

Post-diagnosis dementia care, treatment and support refers to multiple interventions that can improve the quality of life for those with dementia, including both pharmacological and non-pharmacological treatments, caregiving, access to healthcare, support for daily life activities, home adaptations, social inclusion and respite.

“We don't question whether people with cancer need treatment, so why is it that when people receive a dementia diagnosis, they're often not offered treatment or care? Repeatedly, they're just told to get their end-of-life affairs in order,” says Paola Barbarino, ADI CEO. “Coupled with improving diagnosis rates, post-diagnosis dementia care must be recognised as a human right.”

“While dementia doesn't yet have a disease-modifying ‘cure’, there is clear evidence that demonstrates that appropriate post-diagnosis treatment, care and support significantly improves the quality of lives of those living with this disease, allowing many to maintain independence for longer.”

“Globally, clinicians are both under-educated on dementia, and under-resourced to provide adequate post-diagnosis care for people living with dementia,” says Barbarino. “It's up to governments to shore up their healthcare systems so that it's possible for healthcare professionals to provide quality care that people living with dementia desperately need.”

LAF is urging family carers, health care professional to work together to recognize the importance of post-diagnosis care, treatment and support and for the Government /Ministry of Health to incorporate post-diagnosis care into its National Dementia Action Plan .

## *Alzheimer's Disease International - Press release 29th September 2022*

On behalf of the 55 million people living with dementia globally, ADI warmly welcomes the positive initial data reported by **Eisai and Biogen on the results of their Phase 3 CLARITY AD lecanemab study**, that reported that their treatment lecanemab significantly reduced cognitive and functional decline, achieving its primary end point for the trial.

Eisai will now begin discussions with regulatory authorities in the United States, Japan and Europe, with the intention of filing for marketing approval before April 2023.

<https://www.alzint.org/news-events/news/eisai-reports-positive-results-from-their-clarity-ad-phase-3-lecanemab-study/>

## *A Recount of Memorable Steps 2022*

September is world Alzheimer's Month and it is used as a time to spread awareness about dementia and other diseases that shrink a person's cognitive capacities. With the intention of preventing and controlling the disease through increased know how about Alzheimer's, the Lanka Alzheimer's Foundation (LAF) initiated a programme titled 'Memorable Steps' where teams of four or five were requested to walk 115,500 steps per person within a maximum span of 21 days starting from the 1st of September.

Given the close interaction CL Synergy, my current employer has with LAF and given that my own interests in Scrabble have led me to the foundation on multiple occasions in the last ten years or more, I joined one of the teams that signed up from office. I enjoy walking and I have been a part of 'Run for Their Lives' on many occasions, and 'Trail SL' in both phases, from South to North and from North to South, so this seemed to suit me fine.



It took me 18 days to clock in the required steps as one has to carry the mobile for the footfall to be counted. Of late, my own public transport adventures have reduced, as I have learnt to manage with the household quota of fuel.

This recount is to say thank you to my family, colleagues and friends who made each one of those 115,500 steps memorable and I also hope that this article helps LAF in its endeavour of increasing awareness of the disease.

On multiple occasions I took to a walking path in and around Colombo and was greeted with beautiful vistas of the setting sun, the moon or the silhouettes of gorgeous buildings and the illusions created by lamps that dot the paths. The pink and purple skies that reflected off the Diyawanna as I stepped out on day 18 (the day I completed the 115,500 steps) stole the show and my heart. In spite of being a wordsmith (or thinking so of myself), I was at a loss for any sort of word or phrase when I stood by the fence and breathed the beauty of the sky and the water that gurgled at my feet. The image does some justice to what I witnessed, but probably only to a certain extent.

On some days the walks were vigorous and on other days they were more relaxed with time spent drowning in the beauty of the moon, the sky and the stars. On days that I knew I would not be able to make it to a walking path, I would carry the phone on my person as much as possible and let every tiny step count. However, more than the steps that I took towards completing the walk as the 40th, I understand that my role is to be an ambassador for LAF, to speak out loud and clear about this disease which though incurable, can be managed and controlled to minimise the impacts and deterioration of those affected.

Those 115,500 beautiful steps that I took behold memories that I will cherish, each footstep gave me an opportunity to reflect on myself, gave me time to have meaningful conversations with people close to me and helped me to unwind.

Keeping one's mind active and healthy are essential to prevent Alzheimer's. There is widely accepted belief among the experts that close bonds, social interactions and brain stimulating discussions play a significant role in keeping the disease at bay. A healthy walk stimulates the flow of oxygen and blood to brain cells, which again ensures the longevity of the brain. Among a number of other healthy habits, doctors specifically advise people to avoid any sort of head injury.

All of these are doable and require little effort from our end. Head out for a walk, enjoy the skies, the breeze, the dew drops and the exercise for a mentally and physically healthier tomorrow.

A big thank you to LAF for initiating Memorable Steps 2022 and engaging the wider community

By - Praveeni Jayasekera - Chief operating officer (CL Synergy Ltd)

## *Physical and mental exercise - Sunday Observer*

**Physical and mental exercise delays onset of Alzheimer's, and prevents condition from deteriorating – President, Lanka Alzheimer's Foundation of Sri Lanka, Prof. Shehan Williams**

Diagnostic and treatment facilities available in all hospitals

<http://www.sundayobserver.lk/2022/09/18/health/physical-and-mental-exercise-delays-onset-alzheimer's-prevents-condition=>



## *From a Volunteer's Perspective- by Anuradha*



### **My Life with the Lanka Alzheimer's Foundation**

One Sunday afternoon in September 2013, an article titled *Today is World Alzheimer's Day* on the Sunday Observer caught my eye. As I read the article, I learned for the first time about Alzheimer's Disease, and was happy to see the range of free services offered by [the Lanka Alzheimer's Foundation](#) (LAF). This included memory screening conducted by medical professionals and providing necessary information and respite to carers.

When I read that they were looking for volunteers towards the end of the article, I felt convinced that this would be an ideal opportunity for me. I called the number immediately to express my interest, and spoke to Manoja, who transferred my call to Lorraine Yu, the co-founder. After a phone interview, Lorraine asked me to come in every Monday, from the start of October 2013.

I have had great respect for Lorraine from day 1. Her unmatched foresight, warmth and vision has always been an inspiration. Her dedication shows in her approach towards training the staff and volunteers: she leads by example in caring for the clients' well-being and comfort. At the same time, she also made sure that the staff and volunteers felt heard, appreciated and valued. Every event was planned well in advance, and to an excellent standard.

When I first visited LAF, I couldn't believe that I was in Maradana. The entire premises was built to be beautiful, airy, spacious, green and sustainable. For instance, kitchen countertops and pantry were neatly made out of steel and cement. There are fruit trees in the gardens, and there is a beautiful courtyard and a large, well-ventilated auditorium for events. For everyone who visits, the LAF centre feels like a refuge - a sanctuary - where the pressures of our daily lives are left behind, and we get to take in the atmosphere and enjoy the time we spend there.

Working with the clients has been the most rewarding part of my whole experience by far. Clients share what they can of their lives, experiences, and personalities, and we've had several moments of laughter, play and joy. Clients who appear disengaged, confused and/or uninterested at first come alive after a few weeks of coming to the LAF. Most clients thoroughly enjoy the music and singing sessions, sometimes even getting up to dance. Our clients truly come from different walks of life, one client survived the Tsunami, losing all her other family members in the ordeal. Other clients were highly qualified and held very important jobs in their time. Some clients have travelled widely, and share such interesting stories of their experiences abroad.

From the start of 2014, when the LAF started welcoming clients on Fridays, I moved my volunteering day to Friday, and have never looked back. Every day has been a positive learning experience with such outstanding volunteers who so willingly shared their experience in working with clients who have dementia with the rest of us. The volunteers I've worked with since then have now become my friends and I have always felt so happy and proud to be contributing to the LAF.

## *Introducing LAF's new board member*



Mr Nimal Gunewardena is the Chairman of a leading integrated marketing communications enterprise that he founded in 1993, following wide experience in marketing and advertising, and contributes also as its Chief Strategist and Coach. He has 45 years of experience in marketing and communications. Prior to starting his own agency, he was CEO of JWT Colombo following ten years with Reckitt & Colman where he rose to become Marketing Director, and had a stint with AFS Intercultural Programs New York where he was Regional Director for Asia-Pacific. His agency Strategic Alliance was affiliated to several global communications networks including Bates (in advertising) and Burson Marsteller (in PR)

***Questions about  
dementia ?***

**2667080**

Monday to Friday | 9am– 5pm

For information on dementia and dementia care management

## A Carer's Tips - by Ramani Gunatilaka

When my mother was first diagnosed with Early-Stage Alzheimer's Syndrome, I was advised to try to avoid three things: falls, constipation, and urinary tract infection.

Since the likelihood of constipation and urinary tract infection depended on how much water my mother could be persuaded to drink, I needed to allay her fears about not being able to hold on until she was in the toilet and remind her about the extreme discomfort of constipation. I began by seating her on the toilet every morning and giving her three glasses of warm water to drink. Front-loading the water intake made it easier to keep track of how much water she drank, and if we were not meeting the drinking target, saved me arguing about it while the day and my patience wore thin. But while the water may have helped keep urinary tract infection at bay, it didn't do much to prevent constipation, even though she was eating a bowl of fruit every day too. Drinking a lot of water also made her more fearful of incontinence so that she kept going to the toilet and forgetting that she had just gone, with the result that she was spending more time in the toilet than outside.

This could only increase the likelihood of incontinence as the bladder was not required to hold on for any length of time. I consulted the neurologist who prescribed Oxypas. Meanwhile, the geriatrician advised taking Fybogel every day to tame constipation. But then the multiple economic crises struck and both Oxypas and Fybogel disappeared from pharmacies. What follows are the cheap homegrown solutions that we muddled our way towards, which I hope will help others too.

First, I established a toilet log where the full-time carer I had at the time, had to note each time my mother went to the toilet. If my mother refused to accept the carer's word for it, she had to get my mother to sign off on it immediately. Mum was not allowed to go to the toilet again in anything less than an hour. If an hour had passed, then she would be asked if she needed to go, and if much longer than that, taken there regardless, invariably to good effect. Thereafter I introduced toilet breaks at set times to the timetable, like before meals and before her afternoon nap. And most importantly, I made her do pelvic floor exercises, which I supervised. She had to tighten her pelvic floor muscles, whether sitting or standing, and count loud up to ten; then loosen them and count from 11 to 20; then tighten them and count from 21 to 30, and so on until she reached 100. Counting loud helped me monitor while I attended to other things.

As for the constipation, I reduced one glass of water from the morning three and re-introduced it after breakfast as Fybogel on one day (I have squirrelled away a few boxes), and *lunu kenda* the next day. *Lunu kenda* is made by adding a little extra water when boiling raw rice, straining the rice out, and adding a pinch of salt to the starchy liquid that remains. My mother loves *lunu kenda* and is usually happy to have another cup around 11.00 am, when the rice is cooked for lunch. As my stock of Fybogel dwindles, the cheap and humble *lunu kenda* has come to our rescue.

These home-grown solutions have helped enormously: the toilet log has been discontinued and, for the moment at least, other things are moving satisfactorily.

## DATES TO REMEMBER



**Grand SALE**

**Export quality clothing and yummy food**

A wide range of children's, ladies', men's wear and lingerie at bargain prices.

Bring your friends and family and help support a worthy cause!

Saturday  
19<sup>th</sup> November 2022  
10am to 5pm

Lanka Alzheimer's Foundation  
110, Ketawalamulla Lane, Colombo 10, Sri Lanka



**SEASONAL CELEBRATION**

Friday 2<sup>nd</sup> December  
Time 4pm to 6pm

Lanka Alzheimer's Foundation  
www.alzlanka.org

**ICCB BAZAAR - 4th DEC 2022 - AT GALLE FACE HOTEL - TIME : 11 AM to 3P M**

A patient with cognitive impairment who wanders outside alone can easily become confused, injured and get lost.

An identification bracelet can help a loved one with dementia to get back home safely.



Hypoallergenic and Tamperproof ID bracelets are now available at

**The Lanka Alzheimer's Foundation**

**Inquiries Call 0112667080 /82**

## *Current Services*

- Raising awareness and eradicating stigma
- Education on risk reduction
- Education on care management
- Helpline +94 11 2667080
- Memory screening / assessments done twice a month on Fridays
- Activity Centre
- Quarterly newsletter
- Resource Centre/ Information and resource materials
- Caregiver support group (CSG) meeting
- Memory Garden Cafe
- Identification bracelet
- Website : [www.alzlanka.org](http://www.alzlanka.org)
- [www.facebook.com/alzlanka](https://www.facebook.com/alzlanka)

### **Caregiver Support Group (CSG)**

The CSG meetings are conducted as needed .

- support caregivers through discussion and sharing
- listen and learn from care experiences
- share common concerns

### **Collaboration :**

- Sensitise medical students of the Kelaniya University & the Kotelawala Defence University on non-pharmacological approaches to Dementia.
- Practical training for students of the speech therapy unit of the Kelaniya University.

## *The Board*

Lakmali Cabral (Secretary), Priya Fernando, Lilani Jayasuriya, Treasurer)

Beverley Mirando, Romany Parakrama, Nimal Gunewardena , Prof. Shehan Williams (President)

**PLEASE SUPPORT THE WORK OF THE FOUNDATION**

**BY MAKING A DONATION OR LEAVING A LEGACY**

**The Foundation is a Government Approved Charity (Gazette Notification no. 1225)**

Cheques should be crossed and made payable to the **Lanka Alzheimer's Foundation** and sent to Lanka Alzheimer's Foundation, 110 Ketawalamulla Lane, Colombo 10, Sri Lanka

Monthly/Annual donation can be made directly to

**Account number: 106110117418**

**Swift Code NDBSLKLX ,**

**National Development Bank PLC , Havelock Town Branch, (formerly Jawatte Branch)**

**117, Havelock Road, Colombo, Sri Lanka.**

**The Lanka Alzheimer's Foundation is a community based charity and relies on donations in order to sustain the services provided to persons with dementia and their family carers.**

**Your support makes a difference - please give generously**