



Schizophrenia Research  
Foundation (India)

# SCARF ZINE

SCARF INDIA NEWSLETTER

JANUARY - JUNE 2019



# FROM THE EDITOR'S DESK

Dear Readers!

Greetings and good wishes from SCARF!

We are happy to share with you the news letter for the first half of 2019. Henceforth, you will receive this newsletter every quarter. SCARF has been quite busy in these months and we bring you the details in this newsletter. We have had some proud moments like the award for our founder, Dr Sarada Menon, reaching a milestone in our research on genes in schizophrenia and the ground breaking ceremony of the residential facility of DEMCARES project.

We have braved a difficult summer and have managed the water crisis successfully in all the residential centers. Some clients in our residential centers had an opportunity to cast their franchise in the recently concluded Lok Sabha elections ,some for the first time and others after a long break. It not only established their basic right to vote and also served to give them a sense of fulfillment. We are happy we could get this done. We plan to work towards ensuring everyone of our clients an opportunity to exercise their franchise in future elections.

It is encouraging to see participation of service users in raising awareness about mental health issues in recent times. They don't see a need to hide behind anonymity anymore. This is a vital step towards breaking stigma surrounding mental illnesses. The Human library, the webinar and articles by service users in this edition are testimony to this.

We acknowledge and appreciate Team SCARF for its sincere dedication in all that they do everyday to keep up standards.

With best wishes

Dr R Mangala

Assistant Director (Media & Awareness)



# MESSAGE FROM THE VICE CHAIRMAN

## What is the mental health gap?

A lot of attention, globally and nationally has been focused on the mental health gap. In simple terms it means that a number of people with mental health disorders are not being treated and remain so for many years. We have found through our research that this is more in rural areas. In the past, SCARF has adopted many strategies to close this gap, the most significant being the tele psychiatry bus which had a large reach to the never treated. I am happy to say that this has been replicated in many parts of the country and remains a pioneering initiative of SCARF.

The other measure we have used is to create a cadre of community level workers in rural areas who were trained to detect early symptoms of mental disorders, make appropriate referrals, support and inform the families and facilitate simple psychosocial measures of rehabilitation. The STEP programme in Pudukottai is an outstanding example of this. We have now had an opportunity to train community workers in Bihar, Nagpur and other places as well.

Our third initiative to build capacity is the diploma course in Mental Health Care and Counseling which has trained many professionals and others such as teachers, practitioners of other streams of medicine like homeopathy, corporate workers and even family carers in areas of mental health. We expect these trainees to detect symptoms early and make the appropriate referrals. Providing emotional support and simple counseling to those in need will go a long way.

SCARF has reached a stage when we must create replicable models of care and training based on decades of focused work. This is what many others expect us to do as well. We must start face-to-face and online training programmes in many areas such as PSR, research methods, running residential centres, awareness building etc. This way, our collective expertise can make a regional and national impact.

**Best Wishes!**

**Dr R Thara**





## IN A NUTSHELL

### Lifetime Achievement Award



Our Founder & Advisor Padma Bhushan Dr Sarada Menon was awarded "The Hindu Lifetime Achievement Award" at The Hindu World of Women on March 2019.

### Congratulations



Mr Kotteswara Rao, Assistant Director, SCARF India has been selected as state level member for Tamil Nadu State Mental Health Authority (TNSMHA)

### Our clients voted

Our clients from Mahabalipuram centre voted in the April, 2019 Parliamentary elections due to the untiring efforts of Mr Kotteswara Rao, Assistant Director, Ms Karpagavalli, Senior Clinical Coordinator and Mr Bhagavathiraj, Residential manager, Mahahpalipuram.



### Mental Health Diploma Course Batch 2018-2019



The 3rd batch of diploma in mental health care & counseling students successfully completed the course offered by SCARF India in collaboration with NIMHANS, Bengaluru.

### DEMCARES in-patient unit for dementia care

Due to the tremendous generosity of our donors, we have raised 50% of the total budget (3.5 crores), sufficient to start work at the Tamabaram site for the much anticipated DEMCARES In-patient unit for dementia care. The Bhoomi Pooja took place on the 22nd of June 2019. This facility will have 20 beds and will aim to provide services like managing challenging behaviour and facilitating respite care. The facility aims to fill the gap in in-patient services specifically catered for persons with dementia.



# THANK YOU

**We could not have accomplished  
our goals without the support of  
our committed supporters**

**An empowerment program for families of  
persons with first episode psychosis, a new  
initiative by the FEP - First Episode Psychosis  
program of SCARF.**

**READ MORE**

**Page 07**

**18 years of joint research study between  
SCARF and University of Queensland has led  
to the identification of a new clue in the quest  
for causes of schizophrenia, and for potential  
treatments.**



**READ MORE**

**Page 07**

**The Dementia Caregiver Experience Schedule  
(DemCarES) developed by SCARF is being  
adapted and used in Tanzania and Brazil.**

**READ MORE**

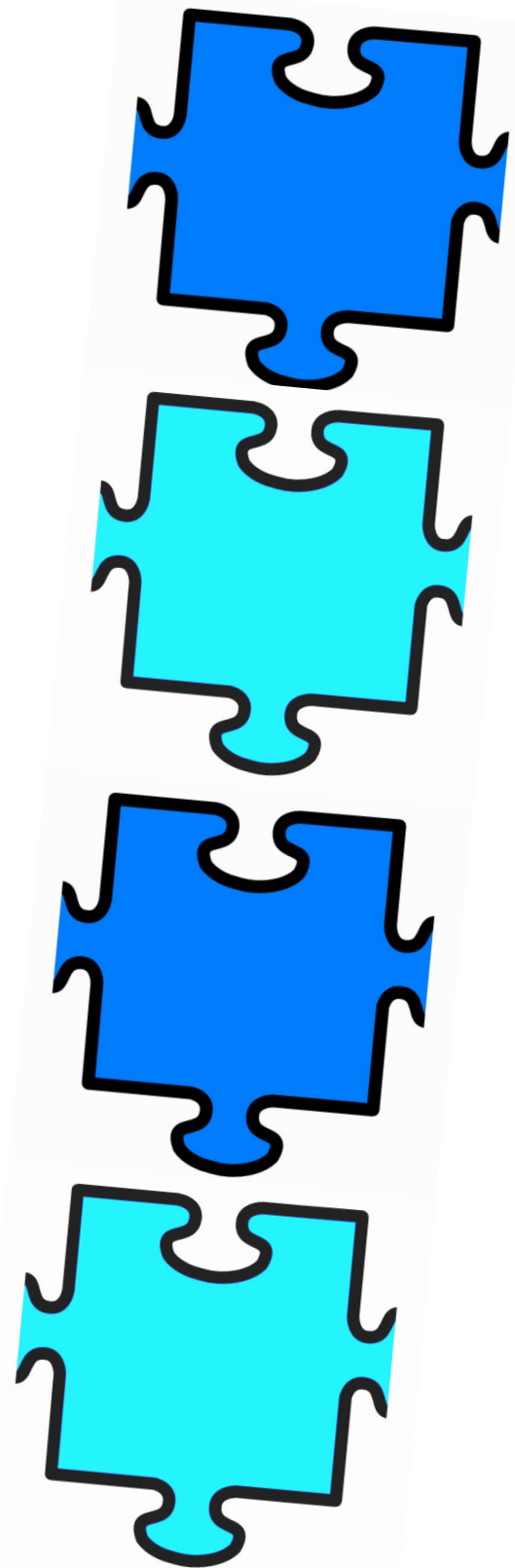
**Page 13**

## HIGHLIGHTS



## What kept us busy!

- The Youth Mental Health team created awareness on positive mental health and did mental health screening for students in various schools and colleges from January to June
- Dr R Padmavati was the chief guest for International Seminar on Creative Art Therapies held at January 29th & 30th organized by the Department of Psychology, Women's Christian College
- Dr.Thara attended the DMHP advisory group meeting at Nagpur mental hospital in February
- Dr R Mangala participated in 2nd Annual meeting of ESSENCE, capacity building project for the development of a digital course on mental health reporting for media professionals, in Bhopal, February
- Dr Shiva Prakash engaged with scouts and guides from the SBOA school at the Tonekala camp in Chennai on the topic of gender equality on February 15
- Dr R Mangala & Ms Annu Joseph attended one-day conference "Reporting Mental Health in Media" organized by the Department of Mental Health Education, NIMHANS, Bengaluru on February 23rd and made a presentation on Frame of Mind film festival on mental health
- Dr Ramesh Kumar and Dr R Mangala conducted a three day training workshop for administration of SCID-5-CV at SCARF India during March 18 -20, for a research group from Pune for a project under DBT-Wellcome Trust
- Dr. Vaishnavi gave a talk on "Elderly Mental Health in Developing Countries - with special focus on India" at the RCPsych Old Age Spring Conference at Aberdeen, Scotland during April -May
- Dr Vijaya Raghavan participated as faculty in Continuous Professional Development course for the counsellors, organized by Niraivagam foundation during May 10th to 12th
- Dr R Mangala gave an interview on "Understanding Schizophrenia" on M Tamil YouTube channel as part of Schizophrenia day.



## What kept us busy!

- Ms Sonia & Ms Omega presented posters on "Group training in Domestic Chores - A pilot experience at SCARF" & "Results of delivering intervention through telephone as an add on to regular face to face session" at the conference "World Association of Psychosocial Rehabilitation" held at Government Medical College & Hospital (GMCH), Chandigarh on May 17th & 18th
- SCARF in association with PatientsEngage (A patient/caregiver focused healthcare platform) organized a webinar as part of World Schizophrenia week, on May 28th. A panel of mental health professionals (Dr R Mangala & Ms Sonia from SCARF India) and persons with lived experience with schizophrenia participated in this first ever event of this kind. It was moderated by Ms Aparna Mittal, Founder and CEO of PatientsEngage
- Dr R Mangala participated in "Red Thiruvizha" organized by Big FM to observe Menstrual hygiene week (May 26th- June 1st). She spoke on mental health related to menstrual cycles
- Dr R Mangala gave a talk on Rainbow FM on Youth mental health and another on Schizophrenia in June
- Dr Shiva Prakash participated in a Health check up talk show on the Kalaingar News channel and spoke on mental health of children and adolescents on June 5th
- Dr Thara and Mr Sujit John attended the International REsearch Programme on Psychoses In Diverse Settings (INTREPID) study review meeting at King's college London from June 10th to 14th
- Mr Rama Krishnan from Youth Mental Health team spoke on Substance abuse to high school students of Aadhi Dhruvidar welfare school on International Day Against Drug Abuse and Illicit Trafficking (May 26th - 1st June)



*Ms Sonia & Ms Omega presented posters during WAPR conference, Chandigarh*



*Mr Rama Krishnan speaking to students*



## New Initiative

### Family Empowerment Program for First Episode Psychosis

*FAMILY IS NOT AN IMPORTANT THING, IT IS EVERYTHING*

The Family Empowerment Program for First Episode Psychosis is an initiative started to empower families of clients with first episode psychosis, which is a distressing experience that families have difficulty in dealing with.

The program aims at providing

- An understanding about the illness
- An understanding about what families and patients go through during the course of illness
- Addressing doubts and queries of illness

Thus this FEP program is designed to

🌿 **EDUCATE**

🌿 **EMPOWER**

🌿 **ENCOURAGE** families and provide hope

and help in the healing process. This program is an evolving one. It was started not just to teach but also to learn from families about their experiences. Meeting other family members during the program helps most of them to gain strength and confidence.



### SCARF – University of Queensland genetic study reveals exciting new schizophrenia clue

In one of the longest running studies conducted by SCARF that commenced in 2001, thousands of people were recruited, diagnosed and screened by the SCARF research team which was largely made possible due to the support extended by patients and their families in enthusiastically participating in the study. This collaboration between SCARF lead by Dr R Thara and The University of Queensland team lead by Prof. Bryan Mowry searched the genomes of more than 3000 individuals and found those with schizophrenia were more likely to have a particular genetic variation. Professor Bryan Mowry said such studies had predominantly been done in populations with European ancestry, with more than 100 schizophrenia-associated variants identified previously.

This study identified a gene called NAPRT1 that encodes an enzyme involved in vitamin B3 metabolism—the researchers were also able to find this gene in a large genomic dataset of schizophrenia patients with European ancestry. In an experiment when they knocked out the NAPRT1 gene in zebrafish, brain development of the fish was impaired. Taking these findings in account the team is now working to understand more deeply how this gene functions in the brain. The research was published in JAMA Psychiatry and supported by the Australian Government National Health and Medical Research Council (NHMRC).

1. Raghavan, V., Mohan, G., Gopal, S., Ramamurthy, M., & Rangaswamy, T. (2019). Medication adherence in first-episode psychosis and its association with psychopathology. *Indian Journal of Psychiatry*, 61(4), 342.
2. Somasundaram, O., & Raghavan, V. (2019). The Romance of Radha: A Journey with Jayadeva. *Journal of Psychosexual Health*, 2631831819850413.
3. Grover, S., Padmavati, R., Sahoo, S., Gopal, S., Nehra, R., Ganesh, A., Raghavan, V., & Sankaranarayan, A. (2019). Relationship of Metabolic syndrome and Neurocognitive deficits in patients with schizophrenia. *Psychiatry Research*.
4. Raghavan, V., & Tharoor, H. (2019). Effectiveness of transcranial direct current stimulation as an add-on treatment for persistent auditory hallucinations in individuals with schizophrenia: A naturalistic single center study. *Brain Stimulation: Basic, Translational, and Clinical Research in Neuromodulation*, 12(2), 408.
5. Chandan, A., Raghavan, V. (2019). Early use of electroconvulsive therapy in individuals with first episode psychosis: A case series. *Indian Journal of Mental Health and Neurosciences*, 2(1).
6. Ganesh, S., Chandan, A., & Raghavan, V. (2019). What we learn about peoples' perspectives on mental health and illness from tweets? *Asian journal of psychiatry*, 40, 26.

### Sheila Mahalingam Yoga and Physical Activity Centre (SMYPA)



In memory of her sister Ms Sheila Mahalingam, Dr Meera Mahalingam sponsored the SMYPA centre at the Vocational Training Centre, SCARF. This was inaugurated on 18th of January by Dr Sarada Menon & Dr Meera Mahalingam for the benefit of clients of SCARF.

The inauguration was followed by a talk by Mr Sridharan from Krishnamacharya Yoga Mandiram on "Yoga and its Positive Effects. " The goal of the SMYPA centre is to motivate persons diagnosed with serious mental illnesses and the treating mental health professionals to incorporate yoga and/or physical fitness as a part of their daily life activities.

## Vocational

### Rehabilitation workshop



A workshop on Vocational Rehabilitation focusing on "Job placement for persons with mental illness" for mental health professionals was organized at SCARF India in collaboration with the Ms Chellamuthu Trust and the World Association of Psychosocial Rehabilitation on 23rd, February.

The key focus of this one day workshop was to train participants in the process of vocational rehabilitation, counseling skills and identifying suitable jobs for the clients and placing them in an open employment. Dr Aarthi Jagannathan, Assistant Professor of Psychiatric Rehabilitation Services, NIMHANS, Bengaluru & Ms Shika Tyagi, Assistant Professor, Department of Psychiatry, GMCH, Chandigarh were the resource persons.

### Yoga Day

Marking International Yoga Day, a session on yoga was conducted on June 27th by Mr D Dwarakanath and Mr Anand from Krishnamacharya Yoga Mantram. Clients demonstrated the skills they had learnt in their daily yoga sessions.



*During Yoga day event*

### Hues of Blue – Art festival

SCARF participated in Hues of Blue - an art festival organized by WOW- Mind & Behavioral clinic to highlight the importance of mental health. This happened at CSI Hr Sec School for Deaf, January 15th to 17th. SCARF had a stall exhibited products showcasing the talents of clients. Pamphlets on mental health were distributed to the visitors and short films on mental health were screened at the event. The response from the sizable number of visitors was encouraging.

### A TIT-BIT

### #ClientsCorner

The main essence or gist of the following narrative is  
"Practice what you preach" or "A law maker cannot afford to become a law breaker"

Once when Belur Math Shri Ramakrishna Paramahansa was preaching his gospel, a middle aged woman along with her young son approaches the swami. The woman complaint to swami was that her sons was too much addicted to or have too much temptation for sweets and sugar and therefore the swami should properly advise him to give-up his addiction or temptation. After hearing patiently to the woman, swami asked her to approach him a week later.

After a week when the woman returned, the swami told her that he asked her to come after a week because he himself was addicted to sweet and sugar and in the course of the interim week, he had given-up his addiction to sweets and now he is in a better position or better place to advice her son.

Thus, "Practice what you preach" or "A lawmaker cannot afford to become a law breaker."

- C R Baskaran



## Linkage of District Mental Health Programme (DMHP) with NGO Services



Dr Lakshmi had a session with medical officers of Ellapuram block, Thiruvallur district on mental health in January, as part of the association with the District Mental Health Programme (DMHP) project.

As part of this initiative, Mr Kotteswara Rao and team organized mental health awareness programmes for self help groups between February to March at the same venue.



#ClientsCorner

ADULT COLOURING  
-A S Akilandeswari



Basically I used to like drawing and colouring during my school days. I used to maintain a drawing file for myself. After finishing college my hobby of drawing decreased gradually. But when I saw the floral patterns in a big sheet firstly I was engrossed. Then I started drawing the outline with the sketch pen which I purchased for this purpose only. I selected small bunches of drawings and closely coloured with sketch pen inside the floral patterns. I did this slowly because the drawings were a bit intricate. I took rest after colouring for half an hour. Even then I coloured bit slowly only. I finished one floral pattern in two days. But, as I followed this schedule I could finish the first three floral patterns in six days. I then realized that there is an improvement in the colouring process, that I completed the next three drawings in just three days. I admit that colouring the floral patterns was an interesting and refreshing task and I showed keen interest for the same as I continued to colour the intricate floral patterns even after gaining the speed in order to maintain patience. I slept well in the nights during this activity.

I could see that adult colouring made me relax well when compared to the time I spent before colouring the drawings. I found that the act of colouring as an important one as I found it as very cathartic. It was a different experience as the earlier ones were small floral intricate patterns but took the entire sheet of the drawing space. So I coloured those small bits with intricate movements of my fingers. Whereas the last drawings was large, where I used big strokes.

This drawing was very relaxing for my finger movements. At last I finished the book during this summer. Lastly I wish to tell that the colouring time was a happy time for me. I refreshed well during the whole activity. My family members appreciated me, each time after I show them my finished drawings and I felt elated for the same. I took this as an encouragement from their side and my mom appreciated me at the end of the colouring activity fully. I wish to tell that adult colouring is very much helpful to solve problems, think clearly, and relax well. Colouring is a happy experience as it is a great stress-buster. It helps to prevent one's mental issues and I am happy to say that I underwent a great experience of adult colouring.

## Youth Mental Health Screening

For the past few years, SCARF INDIA have been conducting programs focused on the youth mental health and have been running it in select schools, colleges and communities. The culmination of our experience and expertise working with the youth in schools and colleges has led to the initiation of a specialist program addressing the mental health needs of youth in schools and colleges. The proposed activities are delivered at no cost to the institution or to the students. As part of the **NIHR - Global Health Research Group on Psychosis Outcomes : WIC Programme**, our aim is to promote mental health education and literacy through lectures and screen for common mental health issues among youth in educational settings. In this process, we have developed a mobile-based application for the screening of common mental health disorders, TrustCircle App, in collaboration with our partner TrustCircle and field tested it in a cross-sectional sample of adolescents and young adults

Basic demographic data is collected and a general orientation to mental disorders was given to the students before the screening through the app is introduced. So far, we have screened students from various colleges and schools in and around Chennai for anxiety, depression and psychotic-like symptoms. The results were shown in terms of mild, moderate and severe of depression and anxiety, respectively.

All the students who took the tests found the mobile-based application to be user friendly. The average time taken to complete the screening tests is around 12-15 minutes. The results were discussed with all the students. A list of mental health services available to the students is provided. The students and the administrators expressed strong support and indicated their support with further research and collaboration.

**6000+**

Mental health screening in schools and colleges so far for the students



### Further steps

- To continue this process to cover the whole of youth population and work closely with the students, teachers and management to promote positive mental health as an ethos of the institution as a whole
- To continue to impart education on mental health literacy and to reinforce the information in regular time intervals for behavioral change among students towards positive mental health
- To create awareness and reduce stigma among the students through mental health literacy to improve access to care and help-seeking when in need
- To examine and develop youth friendly mental health pathways of care within the institution
- Regular screening and follow-up of the students with mental health issues for early care and help. Follow-up of the students at-risk for early identification and referral
- Training the teachers and school counselors to be in forefront as gatekeepers in the early identification and support mechanism for the students in need



## Into the mind -

### Photography contest

*The Winners of the contest*

- How would you portray positive mental health in a single frame? How would you explore mental health issues including anxiety, stress or depression?
- To test it out, SCARF organized a photography contest "Into the Mind" around World Schizophrenia Day in May 2019
- A total of 44 entries were received. The photos were of very diverse themes including, positive mental health, depression, smoking, eating disorder, PTSD & anxiety which is indeed a good start for the first edition. After all, a single picture can speak a thousand words!



### World Schizophrenia Day

- To observe World Schizophrenia Day (May 24), SCARF India organized street plays on the theme "Schizophrenia" at a few parks in different parts of the city followed by an interactive session with specialists in the field. The event was well received by the audience in the park
- People of all ages have signed the pledge banner promising to treat persons with mental health disorders with dignity after watching the street play

### The Human Library

The Human Library is a new concept where people talk openly about lived experience on various issues. This is an effort to break stigma and prejudices.

The Human Library, Chennai in collaboration with British Council had a session on June 30th and SCARF participated for the first time. This is a small step forward in bringing service users discussing their experience in open forum.

Mr Ramana shared his experience of living with mental illness and Ms Annu Joseph shared her experience of living with her family member who has mental illness. The books were well received by the audience.





## Youth Health Mela



*Mind games for students*



*Public talk on Youth Mental Health by Dr R Vijaya Raghavan*



*Mental Health Screening*

SCARF participated for the 3rd consecutive year in the Annual Youth Health Mela held at Valluvar Kottam on June 28th to 30th organized by the Cancer Institute, Adyar. Dr Mangala, Dr Vijaya Raghavan & Ms Subhashini Gopal spoke on "Youth Mental Health" during Youth Health Mela. Two stalls were put up focusing on mental well being and social media addiction. Mental health screening was done for around 100 students and awareness about mental health was made with interests game and activities. Around 250 students visited the stalls.

## Collaborations & project updates - London

*Dr Sridhar representing the Indian teams at the co-applicant meeting (June 2019)*



**The Dementia Caregiver Experience Schedule (DemCarES) developed by SCARF is being adapted and used in Tanzania and Brazil.**

**Cognitive Stimulation Therapy (CST) - International** is a multi-site, multi-centre study which aims to test the implementation of CST in various low and middle income countries over a 3 year period. DEMCARES, SCARF is the lead site for India coordinating implementation of CST in Chennai, Mysore, Thrissur and Delhi. The annual co-applicant for the Global Alliance for Chronic Disease (GACD) meeting was held in London on 24th June. The India team was represented by Dr. Sridhar Vaitheswaran. We are currently working on an implementation plan that will be tested in the next phase. The India team is also working on adapting Alzheimer's Disease Assessment Scale - Cognitive subscale (ADAS-Cog) for use in India.

The London School of Economics team is also helping with the development and testing of Client Services Receipt Inventory for cost analysis of dementia interventions in India, Brazil and Tanzania. Dr. Sridhar Vaitheswaran also had productive meetings with dementia research teams in University College London and with Robotics research team in Imperial College London to plan for future research collaborations.



*CST International Indian sites training by  
Prof. Aimee Spector (March 2019)*

- Cognitive Stimulation Therapy (CST) is a structured intervention for dementia that has a growing evidence base to show improvements in cognitive and quality of life for persons living with dementia. It has been widely adapted in different languages and cultures and used all over the world. Dementia Care at SCARF (DEMCARES) has adapted it for use in India and organized a workshop to train facilitators to deliver this intervention regularly
- There is no pre-requisite of having a specific specialization to deliver this intervention as it is designed for non-specialists to be able to provide it. It is recommended that interest in geriatric mental health or experience working with elderly/persons with dementia is present for those interested in attending this workshop.

## **Health care assistant training programme at DEMCARES**

Health Care Assistant (HCA) training programme is a part of the DEMCARES project with its beginnings in 2015. It was developed based on principles of person centered care practices. It aims to train informal paid caretakers (or HCAs) to be able to understand Dementia and improve communication and quality of care provided for people living with the illness. The sessions are led by Ms. Adhilakshmi Kannan from DEMCARES team. The training happens over a period of two days with didactic as well as practical sessions that cover the basics of dementia, person-centered care, positive communication, and managing difficult behavior. It is continuously improved through feedback from students.



*Adhilakshmi  
with some  
newly  
trained  
HCAs from  
ANEW*

**As of June 2019,**

**230+**

**Health Care Assistant  
have been successfully  
trained**



## Skill Upgradation

- Ms Syed Rabiya, case manager attended an intensive three day workshop on "Acceptance and Commitment Therapy & Dialectical Behavior Therapy" conducted by the Department of Counselling Psychology, University of Madras from 1st to 3rd February, 2019
- Dr R Padmavati and Ms Annu Joseph attended the one day workshop on Social Media for NGOs organized by the Mohan Foundation on February 09, 2019
- To improve services for Dementia in India through the Dementia Services Development Centre (DSDC) and SCARF collaboration, Dr. Vaishnavi from the DEMCARES team at SCARF went on a six weeks programme (April-May 2019) to Scotland to observe and learn from services for dementia provided by the National Health Service. The knowledge gained through the programme will be translated to better the dementia services available at DEMCARES and also in the upcoming in-patient dementia care centre at Tambaram
- Dr. Vaishnavi was with the SENSE-Cog - research team at Manchester during April -May, 2019. The focus is on supporting and improving the quality of life in people with dementia and hearing impairment. DEMCARES will be trailing home based support for persons with dementia with hearing impairment through this project
- Dr Lakshmi and Ms Sonia & Ms Omega attended the conference, "World Association of Psychosocial Rehabilitation" (Chapter 6) held at GMCH Chandigarh on May 17 & 18, 2019. The theme for the conference was "Indigenous and Pragmatic models for rehabilitation: focus for the future"
- Dr R Mangala underwent 2 weeks training on "Women's mental health" at NIMHANS in May 2019
- Ms Monisha Lakshminarayanan represented DEMCARES - SCARF as an early career researcher in the field of dementia at the first annual meeting of the Strengthening Responses to Dementia in Developing countries (STRiDe) project, Cape Town, South Africa. This project covers over 7 countries, including India, and aims to generate a strong evidence base in each country to inform policies for dementia. She also shared the work that is currently being done by DEMCARES for improving dementia care in Chennai



*Monisha with other guest researchers invited for the STRiDe annual meeting at Cape Town, SA*



*"World Association of Psychosocial Rehabilitation" (Chapter 6) held at GMCH Chandigarh*



*Dr. Vaishnavi with the SENSE Cog team in Manchester, UK*



## **ADDICTION**

There has never been a big bad wolf to battle ,  
it's a tiny elf whispering words of encouragement,  
just another puff, another game, another glass,  
the vice matters not, but the elf's safely perched,  
the longer you listen, the deeper grows it's claws,  
until the day comes when you can hear no one else,  
but by then it will be too late,  
you are just a puppet enabling elvish whims.

**#ClientsCorner**

**-Varun Selvakumar**

## **"Bioethics and Ethics Committee Administration" An International Fellow Program**



- Designated among the top 11 Medical Research Foundations in India
- Ranked 4 on H-index (research impact rating) & citations
- Over 85 projects completed
- Over 200 publications in peer reviewed national & international journals
- Recognized by WHO & DST, Govt. of India as a research organization
- Nine ongoing research projects
- SCARF Ethics Committee as per ICMR norms

It gives me immense pleasure to share with you all about the training I attended at the WESTERN INSTITUTIONAL REVIEW BOARD (WIRB) at Washington State, USA. This was an International Fellows Program between March – April 2019 on “Bioethics and Ethics Committee Administration”. Before I move on to describe about the training, I take this opportunity to thank all those who supported me with my travel expenses without which this would not been possible for me. This program features ethics and regulatory training at WIRB in Puyallup, Washington state and at the Division of Medical Ethics within the Department of Population Health at the Medical School for NYU Langone Health, NY. There were totally 8 participants from various parts of the world viz., Ethiopia, Philippines, Kenya, Malawi and Botswana.

With the changing landscape of research in India from the traditional basic and clinical research towards interdisciplinary and translational research involving different specialties and stakeholders, there is a strong need that we need to be aware of the existing ethical guidelines in developed countries and make necessary amendments suiting our context and culture. Being a researcher working in SCARF and coming from a developing country that faces many challenges to be effective in protecting research participants, I felt a strong need to understand research ethics and human rights in a global perspective. We deal with people who lack mental capacity due to their illness and involving them in research and getting informed consent is challenging. There is a need for stringent regulations that would protect them from risks. Understanding the functioning of an IRB, Coordinating and handling the administrative part of the same was another pressing need. The two months program made me understand in depth about the path that had led to the existing ethical principles. Studies done in the past like Tuskegee, Willow brook has made me understand how ethical principles were breached. This program has given me immense knowledge and learning experience in bioethics. I am confident that this will be able to guide and support my organization on the bioethical needs through collaborative work

**-Ms Subhashini Gopal, Psychologist**

## Community Experiences

I have been working as a Research Assistant in INTREPID project (International Research Programme on Psychosis in Diverse settings) for the past 10 months. This project has given an immense experiential learning from the community setting. Theoretically, I have studied that it is necessary to show unconditional positive regard, respect, accept and be non-judgemental towards the clients. This project of identifying and recruiting untreated clients with psychosis from the community has helped me to apply the humanistic approach towards them.



Building rapport with the family in one visit was the major challenge which turned out to be the best learning. After several practice, it helped me to face challenging situations confidently which eventually became the memorable learnings from this project.

I have witnessed some clients having very poor self-care, not having basic necessities of life like food, clothing and shelter, having faced life threatening events in the past, extremely low financial income in families and pitiable caregivers. More than active listening about the situations in a clinical setting, witnessing the same situation in-person made me realise how tough it is to empathise towards them. Yet, this experience taught me to be compassionate. Surprisingly, I perceived most of families in the communities to be welcoming and open minded than I imagined. Their level of trust towards themselves and strangers explains how urban culture is different from rural culture. Though the travelling hours have been quite tedious to reach every client's place, the overall experience has been fruitful and makes me forget my challenges both physically and mentally.

**– Kruthika Devanathan, Research Assistant**

## PEER PRESSURE

There's no hand forcing a drink down your throat,  
no dare that asks you to share a drag,  
yet there's a hole at the bottom of your heart,  
a craving that can't be fulfilled,  
save one word that you yearn for,  
once and forever "us".

Take it from the joker, the lover and the monster,  
the 6 foot bag of muscle loved by creatures young and old,  
you can't carve yourself to fit,  
no matter how hard you try,

so there's only one thing you can do,  
you are who you want to be,  
and you shall always fit,  
all you need to do is forgive yourself,  
for those around you didn't need to,  
forgive yourself,  
for who you are and what you love.

**#ClientsCorner**

**-Varun Selvakumar**



## A Symbol,

getting increasingly famous over the past couple of years,  
representing the biggest choice one could ever make,  
the decision to live beyond an attempt to end,  
but why does that, mean so much to me?  
This story of mine starts at my bed,  
unable to wake, unable to crawl,  
please get up, the heart of mine begs,  
we have things to do, joys to find,  
apathy creeps as my mind laughs,  
what's the use, happiness is a ruse,  
how can you feel, what you have never felt before.

Thankfully that wasn't the end,  
decades later a lesson I shall learn,  
no laughter of mine shall ever be enough,  
for what I seek is smiles all around.  
Thankfully that wasn't the end,  
decades later a lesson I shall learn,  
no laughter of mine shall ever be enough,  
for what I seek is smiles all around.  
A pillar to lean, a hand to lift,  
a joker to all and mentor to some,  
the roles I play and never pretend,  
for all I need is a laugh and a thank,  
from you and you, and you, you and you.  
My nice guy act to everyone around,  
is a selfish, wrong and beyond,

## #ClientsCorner

for gratitude is my drug,  
and I'm one hopeless addict.  
with love, and yours forever,  
Me, myself and my art.

## RELATIONSHIPS AND OBSESSION

Love is blind is what they said  
but deaf and dumb was the packaged deal,  
the bond of two did forgo the world,  
but vice versa? I only wish.  
love's not the answer, nor the end,  
it is but a gentle push towards a path,  
passion, be it any, is kindled fire,  
you can walk in company of glowing light  
or obsess and so shall you burn.

-Varun Selvakumar



## #ClientsCorner

What image comes to your mind when you think of a mentally retarded person? And if you see me in person and compare the two, you will know the whole problem in one second. Mental health is such a taboo in our society. If you can go to a pharmacy to get a tablet for your headache, why can't you consult a doctor for your heartache? Because it is considered a shame to accept you are mentally ill. I have thought the exact same way. I suffer from Bipolar Disorder. I have had 7 different episodes ranging across 12 years.

Bipolar Disorder is unfortunately not that rare as most of you think. Even those who have it think they're in the minority. It means two poles. Two poles of your brain. Two poles of your personality. Mania is the state of extreme joy & Depression is the state of extreme sorrow. Everyone knows depression exists, most of us have unfortunately been through it, and the really strong ones get out of it without anyone's help.



Unfortunately, I was not that strong when I was 13. That was my first episode of depression. And the worst part was me trying to convince myself that I was completely fine and that I didn't need help. I struggled with it by myself for so long and when I couldn't take it anymore I told my family (who were obviously already aware something was wrong with me).

Eventually we sought professional help and I got my first taste of therapy. I have had 4 different episodes of depression in my life. And each of them hurt me in different ways. But luckily, through all of them, I had good people to help me through it. And I didn't hurt anyone except me. And unfortunately my Amma. But depression is good in a way that it only hurts you. So others feel bad for you. Mania is, as I said earlier, the exact opposite of depression. You feel unreasonably happy, overenthusiastic, overconfident, overzealous, basically, for need of a better word, over-everything. I have had 3 separate episodes of Mania in the last 3 years.

It was a dream start to my career in the world's reputed company which was completely blown. I had to leave. Should I say I was fired? Yes, that is indeed the fact. I have blamed myself for so long that I am not able to even consider it wasn't my fault. That is what my mind tells me. And if you hear what my entire mind tells me in a span of 2 hours, you will be shocked. That's just how we are. I fell ill. If I had an accident and lost my leg, they wouldn't have fired me. But I fell mentally ill. And that was something that was not acceptable for them. I had never even failed in a Unit Test in my life. Was it my fault? Yes, I still believe it is. I turned my disappointment into arrogance. I took a month off and said I will relax and get a job easily. Little did I know how wrong I was. 4 months of searching and lots of interviews later, I finally found another job at a great company.

***"If I had an accident and lost my leg, they wouldn't have fired me.  
But I fell mentally ill.  
And that was something that was not acceptable for them"***

The first one cost me quite a lot. More than that, I hurt people who were really close to me. Thankfully, my Anni figured out what was going on in my head before even I knew what was happening. She convinced my Anna and Amma to convince me to go see a psychiatrist. I was adamant that I was fine.

How could I not be fine? I felt I could move mountains. That is what Mania does to you. Let's call the psychiatrist is Doctor X. She consults at the Schizophrenia Research Foundation (SCARF is a cooler abbreviation). It is the best clinic for mental health in the world as far as I am concerned. I buy medicines worth 3000 Rs every 2 months. But have I ever submitted them at my office for medical bills reimbursement? No. Because I am ashamed to admit what I am taking medicines for. Everyone who knows me are aware that I take medicines everyday at 7 pm. I have an alarm for it to remind me. I have given different reasons to different people. But the fact is I am on medication to prevent a relapse of Bipolar Disorder. It cost me my first job.

Now I want to talk to a special bunch of people. You know who you are. There might have been times when you told others that you don't feel all that well, and they might not have been able to help or understand you. But not everyone understands people like us. It is not their fault, they cannot. So don't make the mistake I did for so long.

Please seek professional help. That's the first step to getting better. I would say I am mentally gifted. Yes. Gifted. I have been given a special gift that overwhelmed me and took me apart piece by piece. But with the help of closed ones, I overcame it. And you won't believe the amount of self confidence it gave me once I did. We need to accept the fact that it is ok to fall mentally ill. We should not discriminate or isolate those who might suffer from it. And above all, please educate more people about the importance of mental health.

## TESTIMONIAL FOR THE CENTRE FOR ACTIVE AGING (CAA)

'SCARF' is the place where my husband P Ramakrishnan is taking treatment for 'Dementia' from January 2015. Dr. Sridhar Vaitheswaran and his team are taking care of my husband with a lot of warmth. My husband is attending the 'Centre for Active aging' once a week regularly. Here, elderly people will come together, chat, exchange ideas and views about current affairs and some interesting things that are happening in their lives. There is some time allotted for doing craft work, playing Carrom-board, chess and also drawing. My husband is given consistent care during our visits and we are guided to cope with any sudden, unexpected problems that happen because of the dementia.



'My husband is receiving good care and attention and I am given confidence and support by the team. This care is extended to us even outside the Centre for Active aging in the form of materials, resources and counselling that help us solve everyday challenges posed by the dementia. Even when we are travelling out of the country, the members of the team are always accessible to us and have helped us a lot with problems we have faced every day. I feel a sense of safety and security on the days I visit 'SCARF'.

- Mrs Usha Ramakrishnan

## PHYSICAL AND MENTAL HEALTH: *A review of the relationship*

**Q & A - Dr Shiva Prakash Srinivasan**

"Mens sana in corpore sano" is a Latin quote that is translated into "a healthy mind in a healthy body". While this adage has been used used time and again, we would like to validate this claim with our available knowledge. So let's dive in to look at the available literature and explore this area with questions.

### 1) What is exercise?

According to the Webster's dictionary, exercise is defined as the repeated use of a bodily organ or bodily exertion to maintain physical fitness. In medical parlance, exercise is physical activity that is planned, structured, and repetitive for the purpose of conditioning any part of the body. Consistently, across all definitions used, a few keywords are common:

- Activity: this means that something needs to be done
- Exertion: the extent of exertion may vary according to individual and their level of fitness
- Intent: with the specific intention of maintaining/ building fitness.

Exercise comes in many forms:

- Aerobic exercise: makes your heart rate go up, makes you breathless. Like swimming, running
- Strength training: increases your lean muscle mass. Use of resistance training
- Balance exercise: important in keeping control of and stabilize the body's position. Certain forms of yoga help with this
- Stretching exercises: helps with keeping the muscles and body supple and mobile. Some forms of yoga.

## **2) Has Mental health been studied with physical health?**

- There are sufficient number of studies that have identified the role of poor physical health i.e. chronic medical conditions being an important risk factor for the development of certain chronic mental health conditions such as depression and anxiety. Furthermore, there is a lot of evidence stating that persons with severe mental illnesses such as schizophrenia have a shorter life span, more associated chronic medical problems such as diabetes, blood pressure and obesity. These effects appear to be independent of the treatment of the mental illness and in some cases may be exacerbated by the same. The role of physical health starts off from infancy where healthy children are more likely to perform better at school, be better adjusted in the peer community, have less behavioral problems compared to children with medical problems.
- Physical activity has been found to have a direct effect on peoples mood states with an improvement in positive mood states associated with aerobic activity. There are a multiple mechanisms that have been attributed to this including the “distraction hypothesis” and the “self efficacy hypothesis”. But, what is clearly evident from the data is that there is a biological component of release of endogenous opioids and suppression of immune mediators associated with neurotoxicity. The opioid system is associated with an improvement in mood and the suppression of the neurotoxic effects has been shown to reduce the effects of depression/ other mental illnesses. Certain forms of yoga/ stretching exercises have been shown to be helpful in managing anxiety. In the elderly, early training on balance exercises and strength training have been beneficial in reducing the risks of falls, improving independent activities.

## **3) What do the policy makers say about physical activity?**

The Department of Health and Human Services in the United States recommends at least 150 minutes of moderate – severe physical activity each week. This can be done as 30 minutes of activity per day for 5 days in a week. This recommendation is for typical adults with no significant physical/ mental health problems. Children on the other hand require 1 hour of moderate – vigorous physical activity each day. It is also recommended that children/ adolescents get at least 2 hours of vigorous physical activity each week. Our own government has had the 21st of June declared as the international day of yoga to help improve awareness and physical activity among people.

## **4) What do we do with this information?**

Beyond doubt, getting active is what we would want to do following reading this information. But how? Here are a few tips:

- Listen to your body – your body will tell you what is mild, moderate or vigorous exercise. A good rule of thumb is mild activity is something when you are able to speak without any difficulty while doing the activity, moderate makes you breathless enough to not hold a fluent

conversation while vigorous is sufficient to make you say a few words only.

- Start low, go slow – if you are not used to doing physical activity, starting low and going slow is absolutely important to prevent injuries.
- Be consistent – the most important rule of all because Rome was not built in a day. Changes will come based on the consistency of the activity done.
- Mix it up – different kinds of exercises can contribute to the overall development of the body. It is important to mix it up to give a chance to the body to help it heal and build strength.
- Get a buddy – exercises do not have to be a boring, solitary pursuit. It can also be a place to develop lasting relationships.
- To quote G. B. Shaw – “ we don’t stop playing because we grow old, we grow old because we stop playing”. Keep active and stay young.

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