



forumforautism

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17th December 2021.

ADVISORY COMMITTEE:

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Pediatric
Neurologist

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Pediatrician,
Specialist in
Developmental
Disorders

Dr. Anjali Joshi
Senior
Occupational
Therapist

Ms. Merry Barua
Director,
Action For Autism

Dear Members,

On the occasion of the 19th AGM of Forum for Autism (FFA), we reconnect with you all with a sense of pride and a renewed feeling of hope. FFA has grown from a small motley group of moms into a huge organization with new members being added every day and our networking increasing consistently.

FFA continues in its pursuit of creating a more aware society for our children and adults with ASD, empowering the persons with ASD and their parents, fighting for their rights and creating employment opportunities for our adults.

Run entirely by parents, FFA has achieved many successes and we would like to take this opportunity to share them with you all.

- Regular parent training workshops by leading professionals
- Constant awareness exercises
- Regular engagement with the Government to secure accommodations for our students at school and now, University level.
- Sponsoring of children from un-affording families
- Interacting with corporate houses to encourage our adults to gain employment
- Presenting papers at International Conferences
- Conducting workshops for parents in Mumbai, New Delhi, Kolkata.
- Running libraries where information about Autism is readily available.
- Conducting webinars on various topics account of recent Covid19 pandemic situation, the response of which is overwhelming.

The Monitoring and Resource Committees set up 6 years back are constantly working towards creating safe environments for our children and adults to learn, live and thrive. Committee members have been helping parents in their fight against abuse in schools/therapy centers by being very vigilant. Parents are also empowered to question professionals after attending FFA workshops on Best Practices.

Our presence on Social media too has increased, which will help more families to benefit from our activities.

While there is a lot more to be done, we have reason to believe that the future is promising and hopeful for all our children and adults with Autism.

Please go through our Annual Report to know more about what FFA achieved in the last year.

Please join us in our journey and help FFA help many more like us!



Darshana Chavan Sawant
President



Rajendra Kshirsagar
Secretary



Gururaj Rao
Treasurer

And Core-Group of Parents

**Beena Modak
Babita Raja
Sulekha Doshi
Vijayashree R.
Fatima Shaikh
Radha Iyer
Sarika Chavan**

**Parul Kumtha
Chitra Iyer
Jaya Sudhakar
Chandrika Shetty
Paramita Mazumder
Sunil Salvi
Rajagopal Ramanathan**

**S. Ranganathan
Manjusha Sawant
Alka Baghdadi
Anand Kumtha
Vanishree V.
Shalini Kaul
Vahbiz Mistry**

Forum for Autism - Annual report 2020-21

Monitoring Committee

The Monitoring Committee continue to be vigilant and alert towards any instances of unsafe learning/living environments for our children/young adults. Ideas are shared to ensure safety of students/residents in schools/therapy/residential centers.

Resource Committee

The Resource Committee continued in its endeavor to arrange training sessions for parents and professionals through workshops, talks and Webinars in order to promote its core belief of "ethical means of teaching students with autism".

Parents leading: Beena Modak, Anand Kumtha, Babita Raja, Alka Baghdadi

Activities through 2020-21

Webinar on Trust formation in collaboration with i-Probono

A webinar on Trust formation was conducted by a team of lawyers from Khaitan & Co. Topics covered:

- 1) How to set up a trust?
- 2) Discuss important points of a template private discretionary trust deed.
- 3) Insights on how to choose trusted advisors, i.e. trustees and guardians (for children).
- 4) Discussion on the key considerations and documents that are relevant for parents who have children with special needs.

Speakers:

Mr.Anuj Shah (L.L.B. & Diploma in Securities Law)
Ms.Aditi Sharma (B.A., L.L.B. & L.L.M.)
Mr.Sachin Bhandawat ([B.P.Sc.](#) & L.L.B.)

- Saturday, 23rd October 2021.

Webinar on Sexuality and Developmental Disability

Session includes

- Understand what are the sexual issues that concern individual with Developmental Disabilities.
- Understand what you could do as a parent to mitigate and manage these issues.
- Special educators can learn how to handle such issues in school and workshop settings. Find answers to all those difficult questions that you always wanted to ask but did not know where to ask.
- Various facets of sexuality and developmental disabilities will be covered.
- Also gauge how much you know about the topic

Speaker: Dr.Avinash De Sousa

Consultant Psychiatrist & Psychotherapist. Founder Trustee, Desousa Foundation

- Saturday, 25th September 2021.

Webinar on Anger & Anxiety Management in individuals with Autism

Topics covered

- Understanding Anxiety and its sources in the context of Autism
- Understanding Emotional Regulation
- Anxiety and Anger: two sides of the same coin
- Proactive approaches to manage anxiety
- Self emotional regulation

Speakers:

Ms.Preeti Siwach

Special Educator & Head of Vocational & Employment, Action for Autism, New Delhi.

Ms.Sudhanshu Grover

- o Head of Educational services, Action for Autism, New Delhi.
- o ASD individual, parent to twin adults with ASD & special educator

- Saturday, 23rd October 2021.

Webinar on Autism and Epilepsy

We invited Dr.Pradnya Gadgil for this Webinar. She gave a brief talk regarding Epilepsy and Autism.

Speaker: Dr.Pradnya Gadgil (a Pediatric neurologist and Epileptologist)

- Saturday, 17th July 2021.

Webinar on Nutrition for the child

Session includes:

- Food and Nutrition as essential life skills
- Using Current Diet and Nutrition information to suit child's need. (GFCF diet, camel milk, extra virgin coconut oil)
- Exploring Selective Eating

Speaker: Meghana Surlikar

- Completed Masters in Nutrition and diploma in counselling from TISS.
- Having 15 years of experience in the field of Clinical Nutrition.

- Saturday, 10th July 2021

Webinar on Coping with anger and anxiety for parents of children with Autism.

Session included:

- Understanding the nature of anger & What is healthy and unhealthy anger
- Identifying thought patterns that cause unhealthy anger and anxiety
- Some strategies to deal with anger and anxiety
- Understanding caregiver burnout and some strategies to prevent the same

Speaker: Ms.Sarika Pandit (a Psychotherapist & trained in Advanced REBT)

- Saturday, 26th June 2021

Webinar on Resilience & adaptation at the workplace

Session included:

- Being comfortable with the diagnosis
- Skills to navigate the workplace (Interpersonal skills, Conversational skills, Self-management, Understanding non-autistic world)
- Sensitization of the workplace

Speaker: Preeti Siwach

- Head of Vocational & Employment, Action for Autism, New Delhi
- a special educator, resource person with SSA and NCERT.

- Saturday, 26th June 2021

Webinar on Handling oral care and hygiene for individuals with Autism

Session includes:

- Basics of oral hygiene
- Problems faced by individuals with Autism in maintaining oral hygiene along with the solutions.

Speaker: Dr.Priyanka Engineer

- an Oral and Maxillofacial Surgeon and Cosmetologist

- Saturday, 12th June 2021

Webinar on Managing Family Finances & Succession Planning

Webinar on Managing Family Finances & Succession Planning was conducted by team (Ms.Chitra Iyer & Milin Shah) from My Financial Advisor & Ms.Shreya Jain from Reservoir.

Session includes:

- 1) how to manage your family's finances while securing your child's future
- 2) various aspects of succession planning that you need to consider.

Speaker: Chitra Iyer – a parent & CEO - My Financial Advisor
Milin Shah – Head, Planning at Happyness Factory
Shreya Jain – CEO & Founder at Reservoir.

- Saturday, 7th March 2021.

P-2-P Talk: Breaking the Barriers

We conducted Parent to Parent talk for parents of children with Autism.

In this session, Joanne & Brydan's parents shared their journey of positivity with their children. As parents and advocates for Autism, they talked about how they have been creating awareness & acceptance for kids who are differently abled, asking the world to see beyond the label.

Speakers: Janice & Bryne Rodrigues - Proud parents of Joanne & Brydan

- Sunday, 21st February 2021

Parents leading: Darshana Sawant, Chitra Iyer, Fatima Shaikh, Samrudhi Patkar, Vahbiz Mistry,

Podcast & Consulting session on Financial Planning

Chitra Iyer who is a Trustee of FFA, a CFP (Certified Financial Planner) & CEO of MFA, has been conducting trainings for families to guide them about Future financial security for their special needs kids. She and her team have been conducting one on sessions with Families to also guide them about the legal documents that are to be made for the children. Chitra has worked on The Special Needs Podcast which is available online to guide families about how to think on this important topic. Another insightful part of this Podcast, is the Expert speaker series of Podcast to guide families with their insightful personal experience.

AUTISM AWARENESS

Due to pandemic, we could not conduct any offline event, therefore we celebrated World Autism Awareness Month i.e. April 2021 with series of events scheduled for/by individuals with Autism and their families.

List of events we conducted in April 2021, on the occasion of WAAD.

Sr. No.	Date	Subject	Speaker/ Presenter	Moderator
1	02-April-21	Autism Katta: Connect with Founders	Beena Modak, Parul Kumtha, Babita Raja, Chitra Iyer, S.Rangnathan	Darshana Sawant
2	03-April-21	Online Cultural Event by Individuals with Autism		Y.V.R.Rahul, Rishabh Bhatia & Priya Ramkumar
3	04-April-21	Online Yoga Session	Sunil Ade	Babita Raja
4	06-April-21	Autism Katta: Connect with Parents	Parul & Anand Kumtha	Nirupa & Vijay Bhargar
5	08-April-21	Autism Katta: Connect with Parents	Komal Gwalani	Darshana Sawant
6	11-April-21	Online Cultural Event by Individuals with Autism	-	Atharva Saurkar & Prerna Gwalani
7	13-April-21	Autism Katta: Connect with Parents	S.Rangnathan	Babita Raja
8	15-April-21	Autism Katta: Meet parents who made a difference	Beena Modak, Sushama Nagarkar, Paramita Majumder, Sangeetha Chakrapani.	Parul Kumtha
9	18-April-21	Online Talent Show		Girija Gangoly
10	20-April-21	Autism Katta: Connect with Parents	Vidula Bhat	Darshana Swant
11	22-April-21	Autism Katta: Connect with Parents	Seema & Anupam Tiwari	Vahbiz Mistry
12	25-April-21	Autism: Through the lens of Professional	Dr.Vibha Krishnamurthy, Dr.Anjali Joshi, Dr.Leena Deshpande, Dr.Koyeli Sengupta & Dr.Pradnya Gadgil	Darshana Sawant & Babita Raja
13	27-April-21	Autism Katta: Connect with Parents	Alka Baghdadi & Sulekha Doshi	Beena Modak
14	29-April-21	Autism Katta: Meet the mother butterflies	Radha Iyer, Samrudhi Patkar, Dr.Ashwini Joshi, Prerana Mandle	Darshana Sawant & Fatima Shaikh

Parents leading: Darshana Sawant, Fatima Shaikh, Chitra Iyer, Babita Raja, Beena Modak, Vahbiz Mistry

Online Cultural Event by individuals with Autism

We conducted Online Cultural Event by Individuals with Autism on the **occasion of Independence Day on Sunday, 15 August 2021**. 30 children/ young adults with Autism participated in the event to showcase their talent (like Singing, dancing, playing musical instruments).

Parent leading: Ms.Darshana Sawant & Ms.Fatima Shaikh

Mainstream placement

Webinar on Exploring employment possibilities in collaboration with ASK

Not all graduates in the spectrum can get or can adjust into a white collared job. Hence the need for parents to explore off beat employment possibilities for their wards which they can easily make a career in.

We requested ASK (Adult Support Kendra) to conduct this workshop for FFA. 28 parents registered for the workshop and around 25 attended the workshop.

It was an interactive workshop, an eye opener for many who attended. It helped parents recognise the potential of their wards and help them channelise to a career. Confident ASK will conduct workshop's more often for parents.

Resource Persons: Leela Raj, Nicole Kapadia & Parul Kumtha

- Friday, 23rd April 2021

Parents leading: Ms.Manjusha Sawant

Mainstream concessions

A WhatsApp group has been formed with some FFA Core group members and some parent volunteers of FFA to address the needs of students in different Boards. In the last year there has not been much activity due to the lockdown post the pandemic, the subsequent switchover to online mode of learning and the prevailing uncertainty over the mode of exams and evaluations all of which have been last minute decisions by the respective boards.

FFA's WhatsApp group with parents for mainstream schools (SSC/ ICSE/ CBSE Boards) and NIOS have been active with updates and lot of sharing by the parents. It has helped tremendously to alleviate the anxieties of parents and students in this uncertain academic phase.

All the circulars of NIOS updates have also been regularly posted on FFA FB page.

Parents leading: Darshana Sawant, Vahbiz Mistry, Vijayashree R, Jaya Sudhakar, Rajagopal Ramanathan, Fatima Shaikh.

FFA Website

World Autism Awareness Day pictures and events put up on website. The pictures flow from FFA Facebook page and videos from FFA YouTube channel respectively. All events of FFA updated on website. The recordings of Webinar conducted during lockdown can be seen through the Website.

Parents leading: Ms.Vijayashre R.

MUMBAI MARATHON

FFA participated in the Mumbai Marathon for raising funds. FFA raised around 5.2 lakhs from the marathon driven mainly by efforts from Chef Sanjeev Kapoor. The funds thus raised are ear marked to sponsor school fees of children from un-affording families. FFA right now is sponsoring 8 such children a school for a period of 3 years.

Parent leading: Ms.Chitra Iyer

FFA Doctors Team

- In June 2020, at the height of the pandemic and during the complete lockdown, parents of Forum for Autism who are also doctors, came together to form a task force to assist families seek medical help in the event of Covid 19 infection to any member or to the person with autism.
- The doctor task force is distributed along the Island City, Mumbai Suburbs, Thane and Navi Mumbai and has assisted several families seek appropriate medical attention for both home quarantine and hospitalization.
- The task force periodically puts together important information on procedures and precautions about the virus and facilities and services available via government. This information is shared with Forum for Autism members and on social media.
- This task force continues to give valuable guidance through the opening up of lockdown and continued pandemic.
- The Doctors on the team are

Dr. Ashok Shah

Dr. Meenakshi Balasubramanian

Dr. Sharada Rao

Dr. Ashwini Joshi

Dr. Vivek Birla

Dr. Manjushree Birla

Dr. Supriya Naik

Dr. Saurabh Naik

Dr. Purva Khandelwal

Dr. Vispi Jokhi

Dr. Ashwini Thakur

FFA on Social Media (Facebook page/group, Instagram & Whatsapp groups)

FFA's Facebook page has 5k+ likes & followers. FFA Facebook group now has 5k+ members including parents and professionals. On the fb page Information on talks, FFA's webinar's, live telecast of the webinar's, workshops and cultural events are done (which are 24 in number). Updates on latest resources and therapies, articles, news, etc related to autism is shared.

FFA also has an Instagram page where all the workshop and webinar information is shared.

The FFA group is a wonderful virtual autism family with parents, caretakers & professionals not only from all over India but all over the globe. Here, parents share their children's achievements, emotions, problems, ask queries and are guided by other parents and professionals on solutions & ways to deal with them. We get private

messages from the page too asking for information and resources for diagnosis and therapies for persons with autism.

Files of procedure for autism certificate at Nair hospital and JJ hospital, GR's, Form V, syllabus and resources for COVID help and safety have been put up in the files section of the group.

In addition, there is also a What's app group for Mainstream parents of children with ASD mainly from Mumbai. School issues, concessions for exams, guidance on how to go about it and issues faced by parents in school and at home, academic resources and tips are all shared and exchanged in the group.

We also have a secondary WhatsApp groups of more than 500 members for parents of different age groups (children/teenagers/adults/nios and ffa cultural group) at present. In this group too parents share their problems, queries and other parents guide them. Parents here also look for help and guidance, vent their frustrations and disappointments. Fellow parents hear them out and motivate and encourage them. Parents have bonded and made friendships.

FFA Whatsapp groups

There are 5 WhatsApp groups of parents handled by Core group members.

Name of the Group	No.of Parents
Junior Group	215
Mainstream Group	215
NIOS Group	156
Advocacy Group	136
SSC and HSC study group	22

Parents leading: Fatima Shaikh, Anand Kumtha, Manjusha Sawant, Radha Iyer, Vahbiz Mistry, Jaya Sudhakar, Sarika Chavan.

FFA core members as counseling support

Anand Kumtha (Core Group FFA) and Parul Kumtha (Trustee FFA) continue to offer counseling and employment support to adults with I.D.D. including autism and their families. They are trained in Narrative Practice and are consultants at Adults Support Kendra (A.S.K.) of Yash Charitable Trust.

Advocacy for Ethical and Scientific Methods in treatment and services for autism

Babita Raja (Trustee FFA) and Paramita Majumdar (Core Group FFA) are part of the All India Network for this purpose.

The network has been set up by Adults Support Kendra (A.S.K.) of Yash Charitable Trust and coordinated by Anand Kumtha (Core Group FFA) and Parul Kumtha (Trustee FFA).

The first step towards these ends was to address the issue of over 100 clinics across India selling Stem Cell clinical research trials as treatments and cures for autism and other I.D.D.s. This was done through talks and a Press Note by A.S.K. (Y.C.T.) on the occasion of 3 December, International Day of Persons with Disabilities. Forum for Autism is one of the 44 organizations and 400+ signatories across India, to sign the Press Note.

Navi Mumbai PSG

The Navi Mumbai Parents Support Group was very active arranging help for families that were affected by Covid. Members arranged for home care of young adults whose parents were hospitalised, counselled parents who were going through difficulties managing their children's moods at home during the second wave and supported each other emotionally.

This year's WAAD celebrations also had to be conducted online. Children and parents adapted quickly to the online medium and put up a wonderful cultural show. The program was supported by Navi Mumbai Association of Pediatrics. Senior members of the Association joined the celebrations online and appreciated the efforts put in by the children and parents. They also presented a certificate and a gift to all the children.

Navi Mumbai PSG and Sunshine Education Society, Vashi members were signatories to the press note that was released on Dec 3rd to mark International Day of Persons with Disabilities to protest the unethical use of stem cell treatment for children with autism. Members got articles published in multiple Navi Mumbai newspapers to make parents aware.

Parents leading: Ms.Babita Raja, Ms.Paramita Mazumder, Ms.Shalini Kaul.