

Executive Committee

Neetu Wadhwa - Trustee, Cofounder
Ajit Tolani - Special Advisor
Pinky Thakral - Trustee
Rashmi Bhasin - Project Director

2021 ANNUAL REPORT

[HTTP://SCLERODERMAINDIA.CO.IN/](http://sclerodermaindia.co.in/)
SCLERODERMA INDIA TRUST
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FARIDABAD(HARYANA)-121002

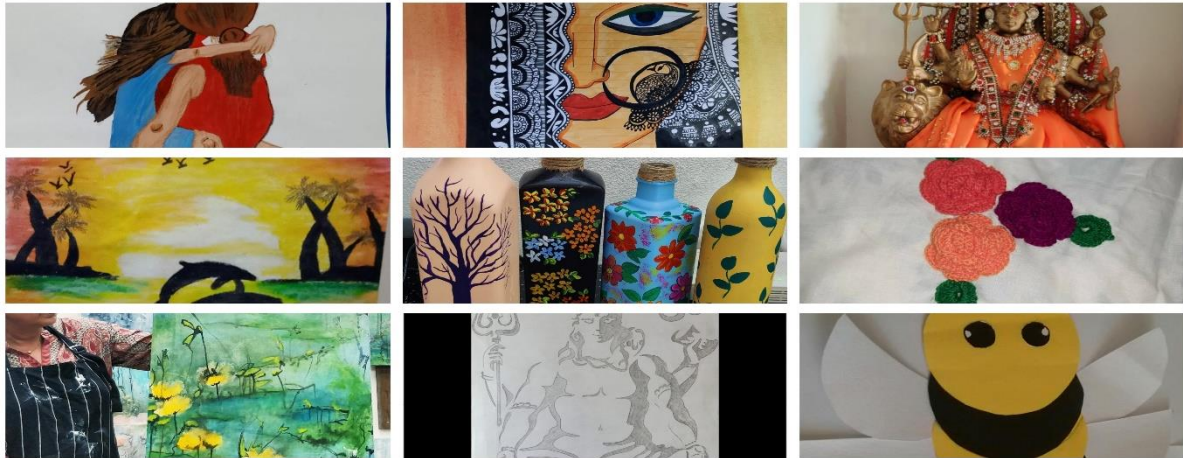


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The Year that went by



We, at Scleroderma India, had a fantastic and exciting year. We conducted multiple Awareness Sessions on various aspects of the disease. It helped us learn new concepts, but we also had a lot of Fun during the Year.

The activities which we undertook were: -

1. Workshop on Yoga -We did a Workshop on Yoga to manage our Chronic condition.
2. We conducted Awareness Sessions on Raynaud's, Ulcers, Digestive issues, and many more.
3. Talent hunt - We conducted a Talent hunt for our Warriors and their Family members. We invited an external Judge, a well-known name in the Artistic field, to judge the event.
4. Invisible illness campaign - We ran Invisible Illness Campaign, where the warriors spoke about what an Invisible Illness meant to them and the people around them and how society perceives them.
5. We got our fellow warriors to talk about their success stories and motivate our fellow patients.
6. We did Fun Sunday sessions where we forgot our disease for a while, and we played games and spoke our hearts out.
7. We started supporting more patients Financially in the last fiscal Year.
8. We tried helping our warriors with Vocational Training.
9. As our priority to robust mental health, we conducted Weekly Meditation Exercises for fellow warriors and their well-wishers to participate and enjoy.
10. We supported patients with 1-1 Or Group therapies with a Certified Trained Counsellor who needed Professional Help.
11. We increased our network with the Medical Fraternity and our collaborations.
12. We were a part of the IRA (Indian Rheumatological Association) Conference, where we put forth our views and concerns.

It was a fruitful year that brought learning and the satisfaction of goals achieved.

Our Volunteers

Volunteers are the backbone of any Organisation, and the same holds good for Scleroderma India. They help with administrative tasks and operations and spread the word in their network.

It is a fact that Volunteering gives a natural self of accomplishment to anyone. With this aim in mind, our Volunteers have come forward from various walks of life, themselves being either Patients or Caregivers. The other reason for some of our Patients and Caregivers volunteering for us is that they believe that the Trust has helped them in numerous ways and want to pay back by serving the patients' community.

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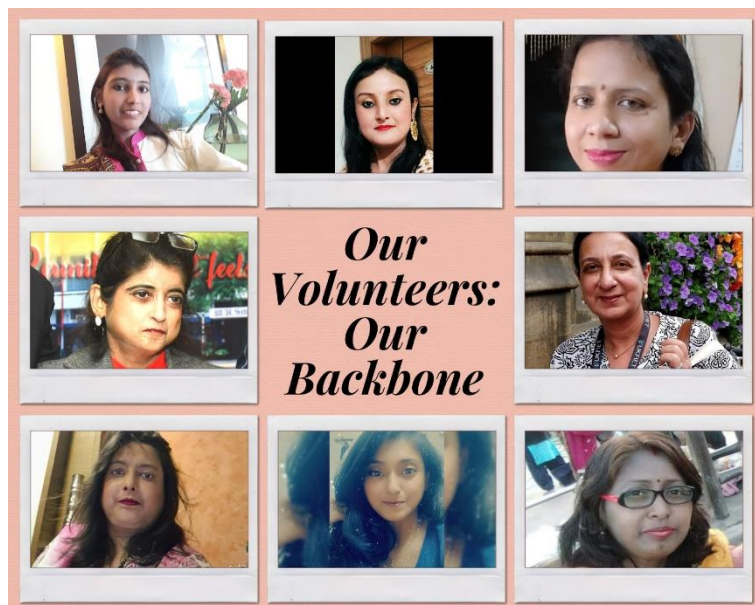
I have gained perspective after talking to Patients and Families. It has fulfilled my life and gives me a sense of purpose now.

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The various activities in which our Volunteers have been helping us out are:-

1. Counseling Patients and Families
2. Curating Social Media Posts
3. Handling Social Media
4. Managing Events/Webinars as part of the Team
5. Working on various projects initiated by the Trust
6. And many more things

Few of our Volunteers:-



Co-founder and Trustee Neetu Wadhwa's Message



Neetu Wadhwa, co-founder and trustee of Scleroderma India, is based in Delhi. She is MBA by qualification and has experience of 14 yrs. in I.T. development and consulting, and she has worked with corporates, startups, and an NGO funded by NANDAN NILEKANI.

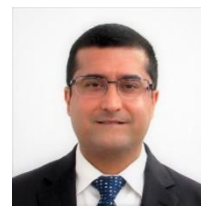
Scleroderma came as a rude shock, but she treated this as a speed breaker and emerged more robust after a short slow down. She realized a considerable lacuna in information about this disease from her delayed diagnosis. She read about the support groups in Canada and the USA. It inspired her and gave her the idea of forming a group in India; she faced many challenges of gathering patients and getting the medical fraternity to acknowledge her, but she didn't give up, and every hurdle made her stronger. She knew it was not only an uphill task, but it was also a battle of mindsets.

People here hid their disease sometimes; they didn't want to acknowledge it. She got in touch with various patient support groups to see how they work. She contacted patients whose references were either given by some Doctor or some support group. She, today, has robust ties with the various patient support group leaders who are fighting for rights for the patients. She is the face of Scleroderma India. She has fought hard to make the dream a registered Charitable trust. She got various organizations to collaborate with the Trust too.

Her mantra in life is to create as much awareness as possible about this disease, and she innovates new methods to keep the group running. A very patient listener, she will never ignore a call or not reply to someone in distress. Her dream is to make this disease affordable for the unprivileged. She believes in "WORK FOR A CAUSE, NOT APPLAUSE."

From the Desk of Special Advisor – Ajit Tolani

Nagpur based Ajit Tolani is an International Tax Lawyer based out of Washington D.C., USA. He is a known personality in the world of finance. He had symptoms of Scleroderma at a very tender age, but delay in diagnosis resulted in him requiring a double lung transplant. He is a powerful man with a very positive outlook on life.



His determination for a good life led him to explore various options in treatment. It was a long journey as treatments for Scleroderma in India still are at a very initial stage; this was why he chose to explore overseas. He decided to shift base after the transplant.

A compassionate person who understood the problems, pain, and expenses involved, he decided to join hands with Neetu Wadhwa, our Trustee, to form the Scleroderma India Trust. He takes an interest in all matters and coaches people who need his Help on the disease and transplant. He works with many medical universities where he acts as a Transplant Councillor for Lung Transplant guidance. He chooses to enrich people with his experiences and learnings, not to face the same challenges as he did.

His vision is to help as many patients as possible and help the impoverished patients for whom this treatment is very strenuous. Though he stays in the USA, he tries to be as involved as possible.

It has been 3 yrs. Since his successful double lung transplant, He has maintained a very healthy lifestyle and lives life to the fullest. His mantra in life is to tread difficult paths with persistence and a positive attitude. From time to time, he shares his experience with our members.

Mark twain says The two most important days in your life are the day you are born, and the day you find out why.". He follows this to a T.

Trustee's Thoughts – Pinky Thakral



Mrs. Pinky Thakral is the trustee of Scleroderma India Trust and has global experience in entrepreneurship.

She is currently a part of the admin team with a Global Educational Institute.

About her journey

Pinky is a friend of Scleroderma warrior, and she is a very compassionate and outgoing person by nature. Her personal experiences issues taught her to be emphatic towards other people.

Being a close friend of a Scleroderma Warrior, she has seen the struggles and challenges.

During the inception days, she met with many doctors and patients and saw their shared goal of fighting this, which strengthened her resolve to make this happen.

She decided to join forces with Scleroderma to help her friend and every other Patient who needed Help. She set her vision to spread awareness and to help other patients.

Her mantra is to create happiness in life by helping others.

According to Ms. Pinky Thakral, her one-liner is

"Help someone even if you know they can't help you back."

Special Advisor's Kavita's Desk

Kavita Chaddha, A special advisor with the Trust, has been a patient of Scleroderma since 2009; she had multiple complications with her physical and mental health. Long before her diagnosis, she had symptoms of Raynaud's. She fought a long and arduous battle with the disease.



After her diagnosis, she felt a hole needed to be filled with information regarding the disease. She started with a Facebook page where she came in contact with Neetu Wadhwa, our co-founder. Both shared the same vision of spreading vision on this complicated disease. They both joined hands and decided to form an NGO. Her Help in the inception days was invaluable. Neetu and Kavita's thoughts, "**Don't tell us all the reasons this might not work. Tell us all the ways it could work.**" made the dream real.

Our Collaborations in the Year 2021-2022

Collaboration - 1 Yoga for Scleroderma for Meditation Session

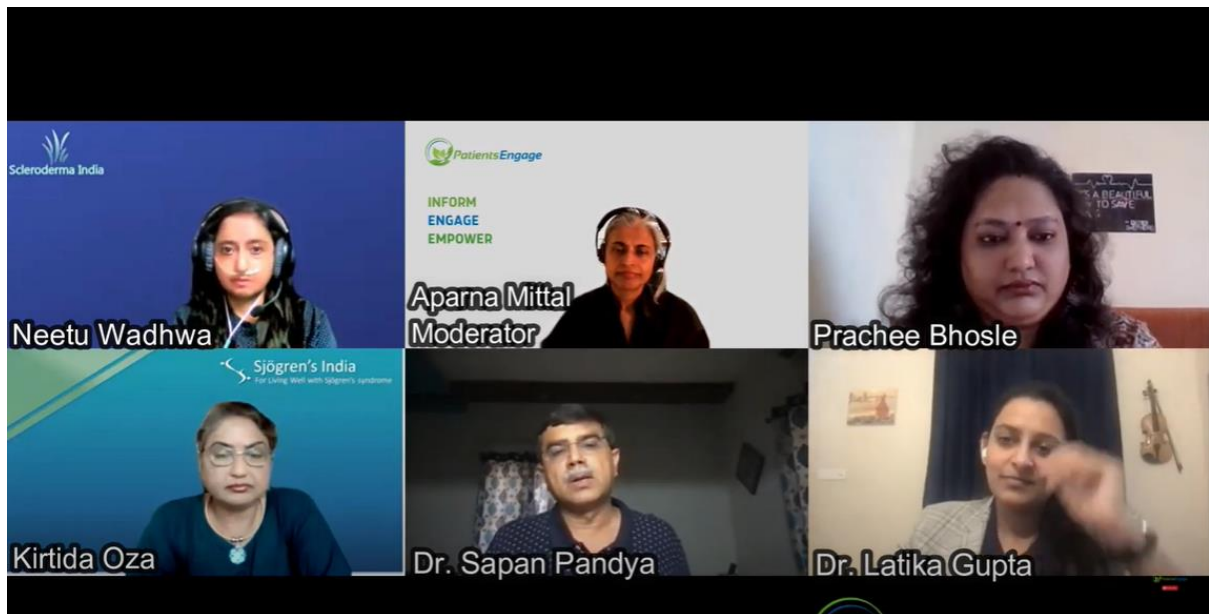


Relaxation Breath-work and Meditations by Yoga for Scleroderma session, "Wednesday Wind-down" - A guided meditation is conducted by a dedicated guide every Wednesday for the fellow warriors to help them in mid-week rejuvenation. The guided Meditation instructs us to relax specific muscles in the body until one is comfortable and leads one through mental images and visualizations. Guided Meditation can be as short as a few minutes or as long as several hours. Either way, the purpose is to achieve mental, emotional, and physical healing and stress relief.

Meditation Sessions with Yoga for Scleroderma is a Trained group of Yoga Professionals. They have developed a comprehensive program of yoga postures, breathing techniques, and guided meditations -benefitting symptoms of Scleroderma. This group also started Guided Meditations for the patients. Guided Meditation is a kind of Meditation where a state of relaxed concentration is invoked and led by another party. It can be a yoga instructor, a spiritual guide, a CD, or even a recording of yourself playing back to you.

The session helps attendees increase self-awareness, patience, and tolerance, reduce negative emotions, increase imagination and creativity, and mainly helps focus on the present moment. These meditation sessions help patients who attend and practice regularly relax the body and the mind. Doing so is beneficial for stress management, sleep, breathing, immune support, healing, Raynaud's, etc.

Collaboration - 2 Discussion on Impact of Rheumatic Diseases on Women on PatientsEngage Platform



PatienEngage, a leading Online Platform related to Healthcare, arranged a discussion on the impact of rheumatic disease in women where our trustee, Neetu Wadhwa, was a panelist.

Rheumatic disease does not affect a person alone but a complete family. Usability to work long hours, fatigue, and invisible symptoms were discussed. Poor awareness and social stigma often force them to hide. Pregnancy becomes difficult.

With Scleroderma, a person's looks change, making women more introverted. Fingers curving, ulcers, narrowing of the mouth are just the tip of the iceberg. Depression sets in, and one loses confidence in oneself. The internal organ gets affected, making life more challenging.

Sexual life gets impacted, which is an essential part of any marriage; extreme dryness in vaginal areas and bleeding after intercourse is common. One also tends to lose interest in sex.

Other group leaders also shared their points of view in the discussion.

Collaboration 3 - IAPO Partnership



International Alliance of Patients Organizations (IAPO) is a London, UK-based Organization, a Nonprofit, Global Alliance. It represents Patients of all Diseases and all countries. They aim to promote Patient focussed healthcare across the Globe. IAPO's member organizations are Patient Organisations working for the welfare of the Patients and their families from the grassroots level to the International organizations.

Scleroderma India became a Full Member of the International Alliance of Patients'organisation in 2021 to build cross-sector alliances and work collaboratively with like-minded medical and health professionals, policymakers, academics, researchers, and industry representatives.

Collaboration 4 - IRA Session - Support group Challenges



Scleroderma India was part of Rheumatologists', Patients' and Caregivers' Conclave - IRACON21 - for the discussion on Support group Challenges on behalf of Scleroderma India. Neetu Wadhwa (Co-founder of Scleroderma India) represented Scleroderma India, a support group that includes patients and caregivers.

Neetu explained the challenges that support groups are facing in India currently. She has examples like; Doctors widespread support required, Doctors referrals to the specialist system should be built, Patient's contribution back to support group is limited, Patients acceptance is a big challenge, and Outreach only to privileged patients. Neetu also threw light on how patients can be proactive by sharing their experiences in the support groups, showing active participation in the events, and volunteering in the support group activities however possible.

Later in the session, Neetu presented a survey where we surveyed a sample which gave us the results of how Scleroderma India to support group helping people in better access of information about the disease (80%), Strength from support group (84%), Help from professionals (90%), Community support (94%). Since India has comparatively less number of Rheumatology doctors to treat Rheumatology patients, the country is very much in need of more and more support groups for patients to support mentally and physically however possible.

Collaboration 5 - IRA Session - Impact of Rheumatic Diseases on the Caregivers

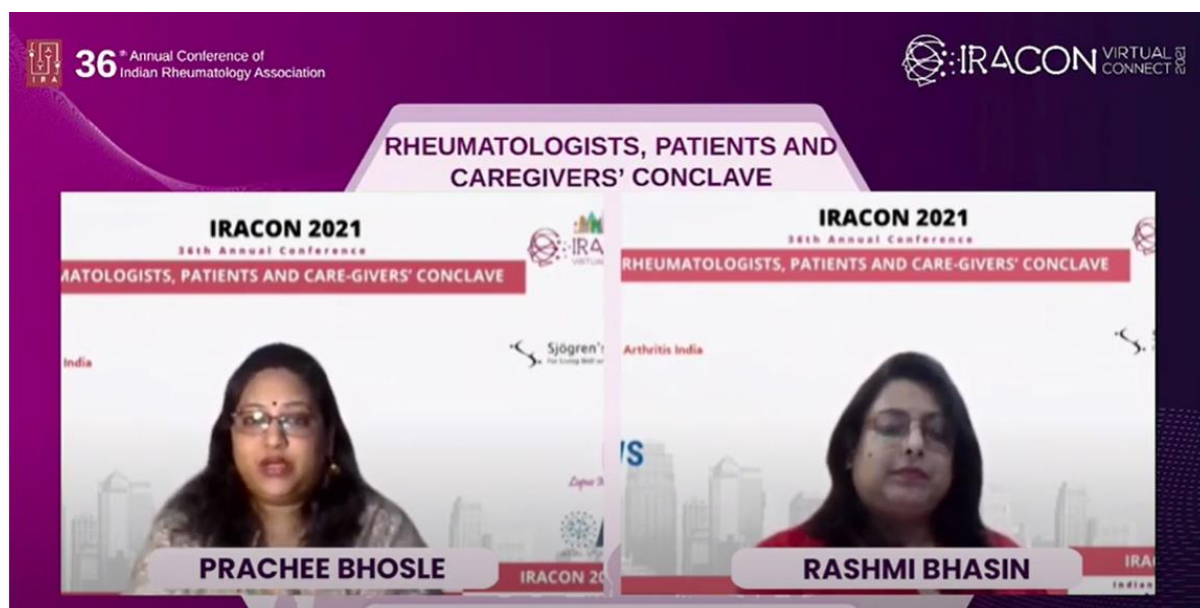


Scleroderma India was part of the "Rheumatologists', Patients' and Caregivers' Conclave IRACON21 "to discuss "Impact of Rheumatic Diseases on the Caregivers." Neetu Wadhwa (Co-founder of Scleroderma India) represented Scleroderma India in the session to discuss the topic. Neetu started with her success story of how her family as caregivers supported her during those challenging health conditions; she has been on oxygen support for a long time. Her parents never stepped back on supporting her. They are helping her with all her medical expenses and keep her emotionally strong in all the situations she is glad about.

Neetu presented another story of caregivers who are the parents of VachasAmrutha (Trustee of Lupus trust India Kerala). They are so cheerful and eager to know about the disease that their daughter is having, and they want to support her both physically and mentally by giving any kind of support. These caregivers are so proud of their daughter that even though she is a lupus disease patient, she is so enthusiastic about doing new things and encouraging other patients towards a positive life. Amrutha has been a young and energetic Lupus warrior for a couple of years, and that disease didn't stop her from meeting her goals. She set an example for youngsters going through the same kind of diseases.

On a similar note, Neetu again brought up another inspirational story of Harpreet, a caregiver to her brother- a sportsperson from Punjab; he was a renowned national hockey player and best athlete till 2003. Then he got diagnosed with Interstitial lung disease and breathing issues. He had to take a lot of setbacks in his career and personal life due to his health conditions. However, still, he didn't give up on it. He worked at a respectable central government job to stand as a pillar for his family, setting an inspirational example for all other Scleroderma warriors for a couple of years. Still, then he has to take premature retirement due to health issues. Harpreet and her family support his brother in all ways to give him good support as much as possible. Again, this is an inspirational story to all the rheumatic patients to sit back and accept and think about how they can cope with their disease.

Collaboration 6 - IRA Session - Impact of diseases on Personal, Professional and Social Life



Scleroderma India was a part of IRACON 2021, organized by the IRA (Indian Rheumatological Association). Delay in diagnosis was a prominent part of the discussion; it explained why the delay happens and how the quality of life deteriorates. There were some videos of Patients and Caregivers shared to emphasize this issue.

Rashmi Bhasin, our Project Director, shared the dais with Prachee Bhosle, President of ASWS. They spoke about the difficulty in getting pregnant and how difficult it is even post-pregnancy to take care of ourselves and the child with Rheumatic diseases. Sexual issues are taboo topics, and these topics are never spoken about. Early menopause hormonal disorders are a few of the other neglected issues.

Few Warriors shared their Success stories.

Mental health issues are Like dust under the carpet, never spoken nor addressed. We got in an expert to talk on these issues.

Several other Rheumatic Support groups from India shared their experiences and gave their inputs

Collaboration 7 – Our Trustee's story sharing at Mission Arthritis India Platform, June 2022



In June 2021, being Scleroderma Awareness Month, Our Trustee and Co-founder, Neetu Wadhwa, was invited by MAI to share her experience and journey with the disease. MAI is the short form for Mission Arthritis India, a Patient Support Group for Rheumatoid Arthritis in India and has been active for 20 Years.

Ms. Wadhwa shared her journey where it was challenging for her to get a proper diagnosis despite the various symptoms. Doctors did not ask many questions to understand the disease and could not correlate the symptoms reported. It took her three years to get the diagnosis right, even though she had G.I. Issues, Acid Reflux Issues, breathing issues, Joint pains, swelling in fingers, and blue fingers.

She discussed how complicated it was for her parents and family to deal with this disease, which gradually progressed over the years. She lost her mobility and slowly came on oxygen support. She transitioned from an independent working woman to a dependent patient who would work from home only when her health allowed. She juggles between doctors, hospital stays, and new challenges every day.

Her takings from her journey are: - giving up is not an option; the disease can be managed with medical advice. The condition can affect your body, but don't let it affect your mind.

Educational / Awareness Programmes

Lata Krishnachand's motivational story

Lata Krishna Chand- A Scleroderma warrior for more than 40 years and an active volunteer for Scleroderma India from the initial days. She is an inspiring woman and always personally motivates all of the warriors in the support group.

She is always active in volunteering for activities in the organization. In the session, she shared her struggles, difficulties living with Scleroderma, and success stories managing her physical and mental health. She got diagnosed with Scleroderma very early in life, and she has managed Scleroderma with her confidence and great positive ability through yoga, Meditation, and exercise.

Ms. SreePriya- A Mental health counselor and mental health social worker who is part of OSTEM - Online Social Support for every mind is a group of mental health professionals volunteering across the country to provide online psychosocial support. The group has well-qualified professionals from leading institutes to support people during stressful times and situations. For example, Scleroderma India collaborated with OSTEM in May 2020 to extend support to their patients during the pandemic.

SreePriya talked about how a positive attitude and motivation help overcome the disease in the session. Also, how a doctor and patient relationship helps treat a disease. She spoke about how stress, anxiety, depression, and work tension may affect a person's health. She also pointed out how a daily routine affects patients' mental and physical health and improves patient condition through a healthy daily routine.



Scleroderma Family Get Together

As a Support Group, Scleroderma India completed 6 Years on May 2021. Hence, we held a Talent Show to celebrate that so that the family and friends of the Scleroderma family could get together for some fun through the fun-filled competition. We Invited the Entries for Art/Crafts/Dancing/Singing etc., from the Support Group members and their family members. The event's Grand Finale was conducted the Last weekend on May 2021.

Neetu Wadhwa (Trustee and Co-founder of Scleroderma India), Rashmi Bhasin (project director at Scleroderma India), Pinky Thakral(Trustee of Scleroderma), Ajit Tolani (Adviser and trustee for Scleroderma India), and Angana Barua(Volunteer at Scleroderma) conducted the session.

Ms. Sangeeta Vyas, who is settled in Mumbai and is a singer and voice-over artist, is a multi-talented person and judged the competition at the event.

Ajit Tolani's and Sangeeta's speech was inspiring to all the participants. Also, it was a pleasure to have Kavita Chadda (a fellow patient and co-founder of Scleroderma India) There were different genres like arts and crafts, drawing, poetry, dance, and singing. In The event, not only Scleroderma patients but also their family members had participated. All the participants were talented, and the judges felt it was unfair to choose a single winner. It was a very entertaining and fruitful event that everybody enjoyed.



June Scleroderma Day Session with doctors & Patients

June is the scleroderma awareness month, and we did a live session with expert doctors on the Advancements in Scleroderma Treatment.

Streamed live on June 27th, 2021, it was sponsored by IRA- Indian Rheumatologist Association- IRA has a mission of providing support and assistance for Autoimmune disorders and other Musculoskeletal disorders.

The session was hosted by Neetu Wadhwa (Trustee and co-founder of Scleroderma India), Rashmi Bhasin (project director at Scleroderma India), Pinky Thakral (the trustee of Scleroderma). It was a successful session with reputed doctors sharing their thoughts and knowledge with the participants.

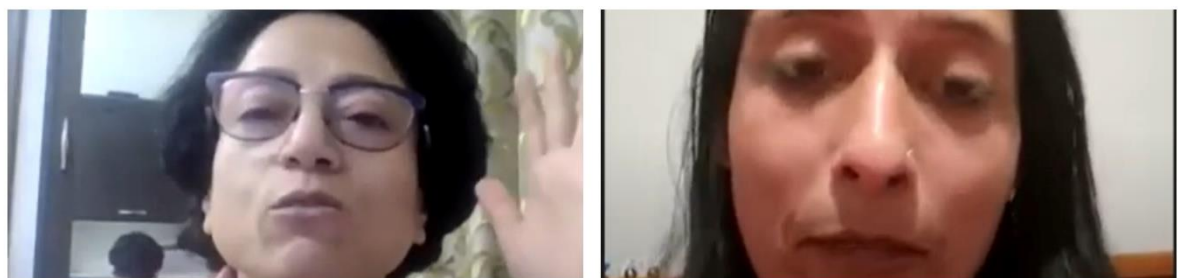
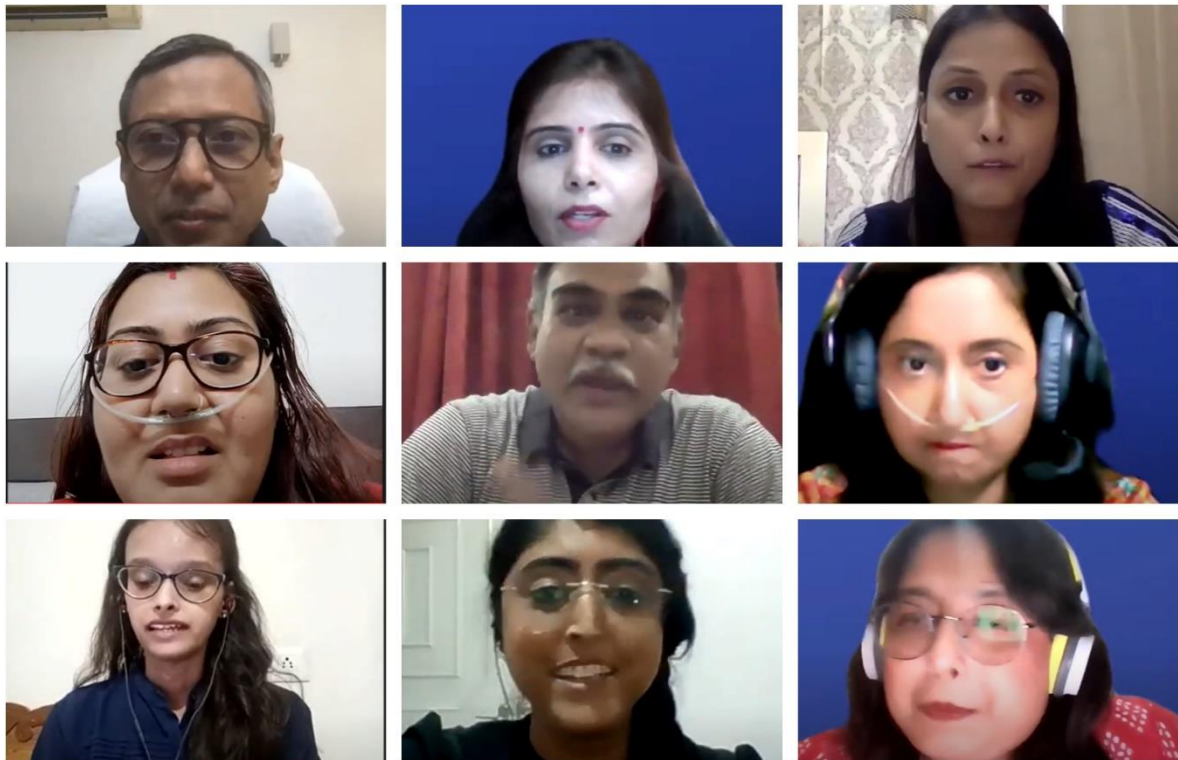
Dr. PD Rath, the director, and head of the Department of Rheumatology at Max hospital Delhi, has 20 years of expertise. It was awarded the best Rheumatologist in 2019. His take is "Knowledge dispels fear" -Knowledge helps us calm our emotions. He presented slides on how Scleroderma affects skin and lungs.

He threw light on new medications and new ways to treat them. He spoke about anti-fibrotic drugs called Pirfenidone and Nintedanib, which are very advanced and essential medicines in helping with lungs damage. He also explained about tests to know the stages of Scleroderma. He also explained about Stem cell transplant in treating Scleroderma.

Yogita Sharma and Ashwini Nalhe (Scleroderma warriors) shared their experience with Scleroderma and their procedure for finger and lips treatment. Ruchi Mittal, also one of the Scleroderma warriors, explained her story about how she managed her married life and pregnancy with Scleroderma. It was fascinating to listen to all three of them.

It was great to have Dr. Vivek Singh, a Consultant, and a Transplant pulmonologist at Kims hospital Hyderabad. He took a session on symptoms of Scleroderma, how to identify lung involvement and how to treat it at different stages. He also explained Lung Transplant options and how to manage the disease before it becomes complex. He spoke about nutrition for the Patient and exercises that Scleroderma patients should practice daily.

We had a Q/A session at the end to address any queries or concerns.



Lung transplant

- For patients with advanced lung disease who continue to be symptomatic despite maximal medical therapy lung transplant can be a treatment option.
- Lung transplant not only improves the

Dr. Vivek Singh...

Limited and Diffuse SSc— Skin Involvement

Dr. P D Rath

Yoga for Chronic Diseases

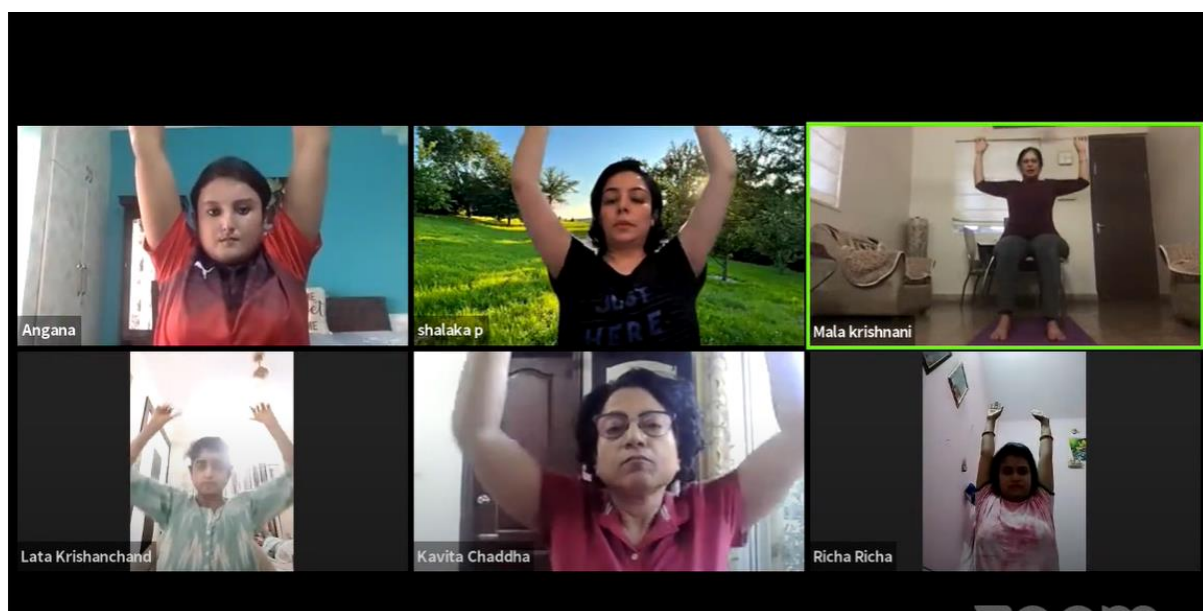
This webinar was about **Group Yoga Therapy for Person Living with Scleroderma and Pulmonary Hypertension**. Our esteemed guest-Ms, **Mala Krishnani**, presented this webinar. She is a trained yoga teacher from **The Yoga Institute, Mumbai**, with a teaching experience of more than 20 years.

In this webinar, she spoke about some yoga exercises that everyone can efficiently perform in their comfort zone.

Chair Yoga- Sit on the chair, join both hands in namaste mudra, and do prayer for 2 minutes whether eyes are open. After that, she demonstrated a few of the exercises. Like exercises of knees, elbow, feet, fingers, wrists, shoulders, ankles, toes, etc. Some benefits of doing these are to remain an active and pain-free movement of every joint. In addition, it improves blood flow, improves posture, increases energy level, and reduces inflammation of joints.

Asanas- Some accessible forms of Gomukh asana, Mastinger asana, Konasan can perform daily to overcome health issues of the spine, shoulders, spondylitis, and arms.

Breathing exercises involve practices like Chinmay mudra, Intercostal breathing, Caricular breathing, Diaphragm breathing, Belly breathing, and alternate nostril breathing. The primary purpose of all breathing exercises is to regulate our breathing smoothly, calm down anxiety, increase the strengthening of lungs to hold more oxygen, improve our immunity, act as a natural painkiller, improve blood flow, increase energy level. By doing these Asanas regularly, we can live life smoothly.



Freedom Campaign

Scleroderma India conducted a Freedom Campaign in August 2021 to celebrate our Independence Day. We celebrated August as a Month of Freedom from the thoughts of our Chronic Illness. All participants were dressed up in tricolor. We started our program with the National Anthem sung by Ms.Lata.

The other activities which we undertook were:-

Patriotic Songs-Many participants sang patriotic songs, and these songs motivated us.

Rangoli-Our minor participants sent pictures of beautiful tricolor rangoli.

Motivational Thoughts and Poem-Ms.Rashmi presented her inspirational thought to represent the value of freedom in our life. Ms.Angana recited a very motivational poem.

Tricolor Dish- One of our participants prepared a tricolor dish during this celebration. Our primary purpose in celebrating this day was to pay tribute to our freedom fighters and respect our freedom. It was an evening well spent



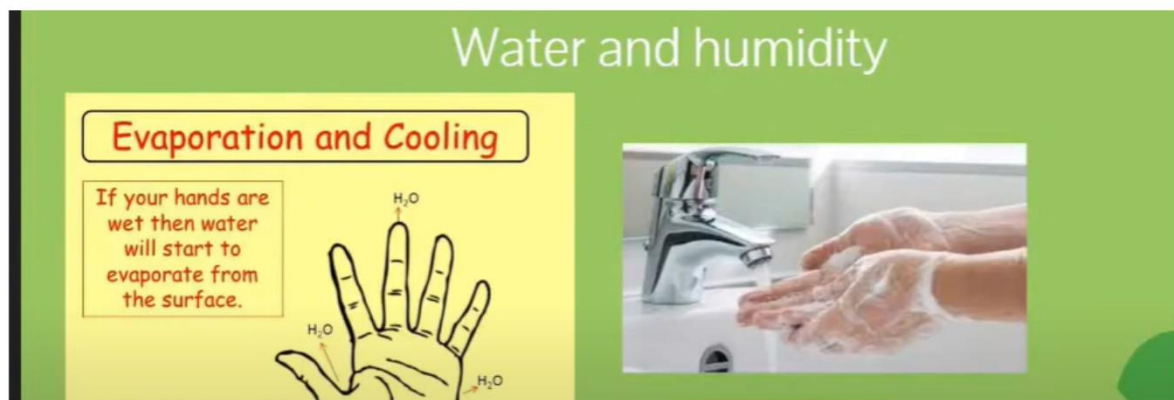
Raynaud's and ulcer management with Ajit Tolani

Ajit Tolani, an advisor with Scleroderma India, conducted this awareness session. He is a double lung transplant survivor and a fellow patient. He is based in the USA and ever ready to help fellow patients.

He has had one of the worst Raynaud's episodes one has seen. He spoke about peripheral Vascular problems caused by Scleroderma - Vascular issues happen due to constricted blood flow, which results in Gangrene. Natural or artificial cold is one of the culprits. Stress, anxiety, low cardiovascular activities play spoilsports.

Vaso dilators like tadalafil are prescribed to manage this. Exercise is an essential part of managing this condition. Wear gloves while doing water work or massage for better circulation. Diet plays a significant role too. Eat the right food, do not hold cold glasses directly, wear gloves, especially at night. Hot water therapy can help a lot.

Mental health plays a significant role in controlling any disease; the same holds for this condition, too - Meditation helps; talk to mental health advisors if required. He shared a lot of tips to manage the disease. The session ended with Q&A.



Acid Reflux management with Mr. Ajit Tolani:

Streamed live on November 21st, 2021, The session was hosted by Ms. Neetu Wadhwa (Trustee and co-founder of Scleroderma India) and other volunteers from Scleroderma India.

Ajit Tolani, an Advisor with Scleroderma India Trust, leads the session to understand Acid Reflux management with Scleroderma. He talked about how Scleroderma affected his daily life and about his journey with a Lung Transplant, which was successful. He also explained all the signs of acid reflux in the body and how to fix it. The session was informative and gave us an understanding of the causes and complications of Acid Reflux.

Ajit spoke about ways to manage it with some daily routines and change how we sleep, like using a Wedge Pillow. He also highlighted the complications and explained how lifestyle changes could help us manage them better.

There was a Q/A session at the end to clarify any queries from the participants.



Ulcer Management in Scleroderma

Scleroderma india did a session with Dr. Kaushik Bhojani. He is a Rheumatologist from Mumbai, having experience of 25 plus years, and is running a center called Kennisha in Mumbai.

He started the session by showing different pictures showing how skin hardens and fingers curved because the blood circulation is hampered, which results in Raynaud's. Ulcers start forming for the same reason, which is very painful and infected. Hands and fingers seem white because of less blood circulation. Gangrene also is developed in some cases, and amputation is required.

He spoke about covering the nose and ears for protecting hands and feet, And a few other tips like:-

1. Wear warm socks at night.
2. Wear gloves.
3. Place heaters in cold places.
4. Wear rubber gloves for washing utensils and doing water work.
5. use Luke warm water for washing

He spoke about creams, stickers, and medicines to increase blood circulation. Keep the ulcers clean and dry. Use an antiseptic powder after showering on ulcers and Use betadine to clean them.

The session ended with Q&A.



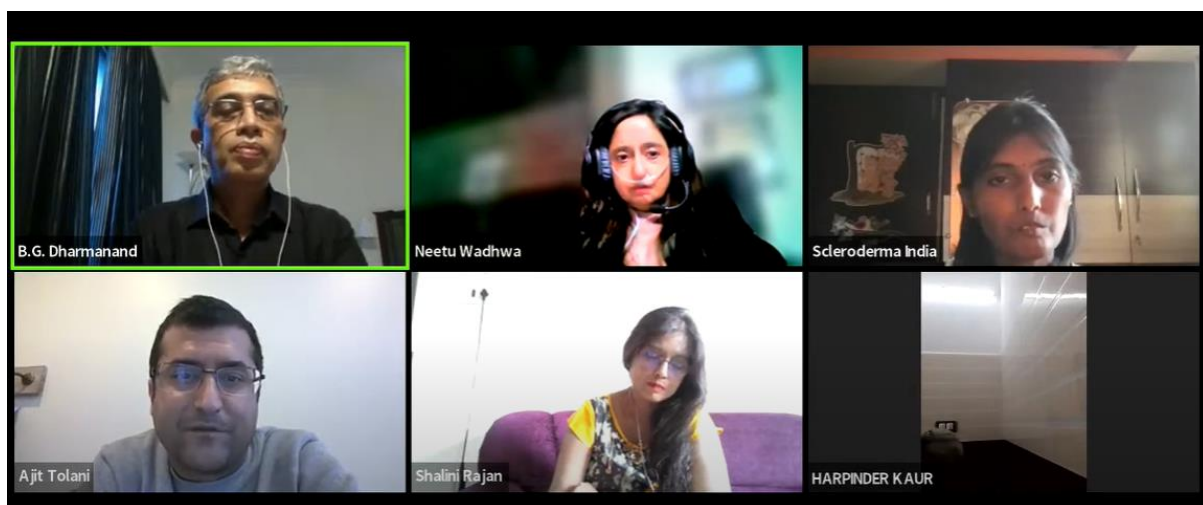
Gastrointestinal Issue in Scleroderma by Dr. BG Dharmanand

Scleroderma India invited Dr. Dharmanand to speak on Gastric issues, which are of significant concern and less spoken; in Scleroderma, he is the current IRA president. He is the head of the rheumatology department at Manipal hospital, Bangalore.

He explained how the digestive system starts from the mouth and ends at Anus. And how reduced saliva, dry mouth, and reduced opening of mouth make digestion more difficult. He spoke about GERD issues with the esophagus and explained that dry cough could signify acute acidity.

He further spoke about how the stomach and small intestine also get affected. Indigestion is very common. Acid is required to digest food, but many issues occur as the patients are on acid-suppressing medicines. The liver, colon, and Anus are affected as well. Constipation, diarrhea, burning in the anal area, leaky gut, and fecal incontinence are all part of this disease.

He then spoke about the management of GI issues. He mentioned a few things which can help patients:- maintaining hydration, dental care, weight management, avoiding alcohol, avoiding smoking, avoiding chocolates, avoiding dairy, head elevation, Taking in high Fiber food, eating a small meal, using the squatty potty, yoga, etc. Ajit Tolani, our trustee, shared his story around GI Issues, and the session ended with Q&A.



Raynaud's Awareness Month

February is celebrated worldwide as Raynaud's Awareness Month. We at Scleroderma India too celebrated this by creating awareness about this medical condition and providing information about available treatment options.

We ran a contest where we encouraged people to talk about their personal success stories with Raynaud's. A couple of people shared their stories about overcoming the problems faced due to the disease with minor changes in their lifestyle. We had our warriors sharing their stories, which motivated many more people to take care of themselves proactively.

We declared two winners too, from this Contest.



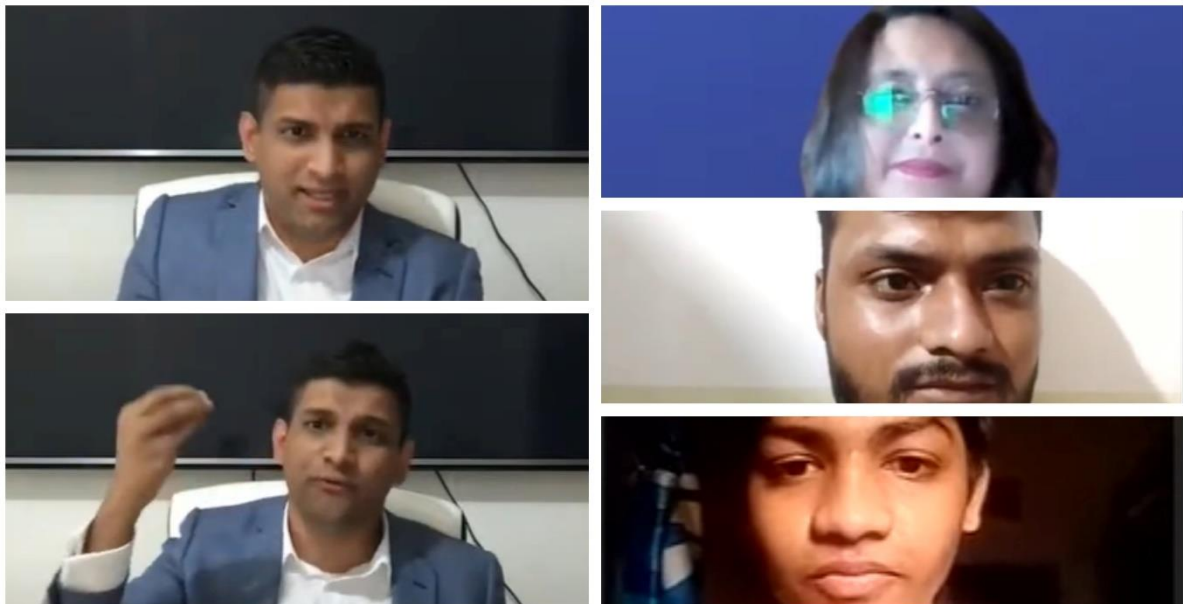
Deek's Session on Life Positivity

We conducted the last session of the Year with Deek Prassani. He is a life coach and a motivational speaker. Deek Parassini is on a Mission to make positivity free for All, and he believes that "Life is All Positive and Negativity doesn't Exist."

He is the founder of LIAP - "Life Is All Positive" Foundation, a volunteer-based, humanitarian, non-religious, non-political organization with a vision to make "A World filled with Positivity." We are all born positive, so there is positivity within each of us, and this community is created to make people realize this positivity. There are over 5 lakh members in his social media community, and 11,000+ Members in his "Life Is All Positive" WhatsApp Group, and the numbers are still growing.

Our members very keenly asked him doubts and questions about their lives and careers, which he patiently answered. This session was an experiment for us that did very well.

Our Year ended on a note of Positivity on International Happiness Day.

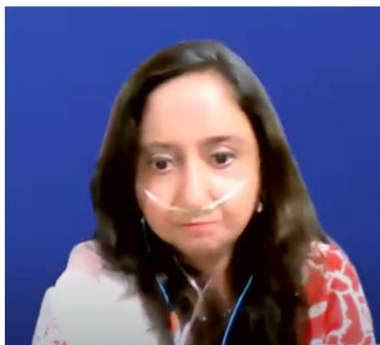


Sunday meetings

We started our sessions on Sunday - informal meetings in the Year 2021. We decided to get them to know our fellow patients better and understand them better. We gathered here to gossip and share our pains and joys. We played games and shared information. We made friends with people who we knew only by name.

We learned a lot from these sessions too. We learned to address their needs better. Our fellow patients shared their fears and anxieties with us, Shared personal issues without hesitation as they have established the Trust and bond.

These are only fun sessions where we forget our pains and disease for some time; we are like ordinary people who have gathered for Fun.



Our vision for Future

We learned a lot of new things last Year, failed in a few succeeded in some. But the new Year is a new beginning.

We have a lot of things planned out, and we want to increase our database not only with patients but also with the Medical Fraternity.

Scleroderma is a very complex disease. Therefore, We want to support more patients with information and finance to have a better and easier life.

We want to give our warriors training to get independent financially. In addition, we want them to be more strong mentally so that we will work in this direction.

THE FUTURE IS COMPLETELY OPEN, AND WE ARE WRITING IT MOMENT BY MOMENT - PEMA CHODRON

