

Annual Report

APRIL 2020 - MARCH 2021

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Scleroderma India at a glance



What can Scleroderma do to your life?



Can you see the two faces of the same person?? This is what scleroderma does to you. Hiral, a dynamic lawyer, Couldn't realize her dream of becoming a successful lawyer as this disease cost her untimely death. She had to be put on a feeding tube, too, due to severe damage to the gastrointestinal tract



Neha Patel, an academician, from Gujrat, had dreams of getting into the profession of teaching but her physical limitations cut short the aspirations. She likes singing and writing/reciting poetry.



Our Vision

Neetu Wadhwa (co-founder of Scleroderma Trust), and Kavita Chaddha (a fellow Patient), when diagnosed, went through many perils of detections, misconceptions, griefs of having an ailment which is not known to many. There were mixed reactions even in the medical fraternity. All this gave them the motive to start with the support group, the illness was there, but the information was not available.

Scleroderma is a very complex disease; no two people suffer the same symptoms, nor do they have the same medication. It leaves many clueless about the condition and treatment. There was no common platform for these patients to come and share their fears, pains, and woes. They started a chain with links joining in.

We wanted this platform for patient support and provided them with medical aid, mental support - through mediation, yoga, alternative therapies. It was a mountainous task as people were unwilling to come forth with their stories or symptoms; social stigma and taboos were there. It took us few years to form an active group.

Our Vision

Today we are a registered charitable trust with a dynamic working committee. Every month, we have meetings to keep our fellow patients updated with the latest developments on the treatment; we also have sessions for mental health and sometimes just fun and frolic.

We fulfilled one more of our visions by helping a few underprivileged patients financially.

We still have miles to go before we can rest, we are striving, and we will do our best to fulfill our goals.

Statement of the Founder



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

Scleroderma came as a rude shock, but she gathered herself together with the strong lady she is. She saw there was a huge lacuna in information about this disease. 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. 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 even didn't want to acknowledge it to themselves. She got in touch with various patient support groups to see how they work. She personally contacted patients whose references were either given by some Dr or some support group. She, today, has robust ties with the various patient support group leaders where they 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.

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. She fits the quote perfectly "LEADERSHIP IS ABOUT BEING OF SERVICE TO OTHERS, NOT BEING SERVED BY OTHERS. BE A MENTOR, NOT A BOSS"

neetu@sclerodermaindia.co.in

Statement of the Trustee



Delhi-based Ms. Pinky Thakralis, the trustee of Scleroderma India trust and has global experience in entrepreneurship. Now she is currently a part of the admin team with a Global Educational Institute.

Pinky is a friend of a Scleroderma warrior. She is a very compassionate and outgoing person by nature. Being a close friend, she has seen the struggles and challenges of a Scleroderma Patient, which motivated her to join forces with Scleroderma India. During the inception days, she came in touch with many doctors and patients and saw their common goal of fighting this. This helped her get her to resolve stronger and work in this direction.

She decided to join the team of Scleroderma India to help her friend and every other patient who requires support. She set her vision to spread awareness and to support other patients.

Her mantra is to create happiness in life by helping others. She believes in “Help someone even if you know they can’t help you back.”

pinky@sclerodermaindia.co.in

Statement of the Special Advisor



Born and brought up in the Nagpur area, Ajit Tolani is an international tax lawyer based out of Washington D.C., USA. He is a known personality in the world of Tax Litigation. Symptoms at a very tender age but delay in diagnosis resulted in him requiring a double lung transplant. He is a resilient 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.

A very compassionate person by nature who understood the problems, pain, and expenses involved, decided to join hands with Neetu Wadhwa, our trustee, in the formation of the scleroderma India trust. He takes an interest in all matters and makes sure to coach people who need his help on the disease and transplant. He has associated with the Cleveland Clinic acts as a counselor for lung transplant patients. He endeavors 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, especially the destitute patients for whom this treatment is very strenuous. Though he stays in the USA, he tries to be as involved in Indian and Global patient cases as possible.

It has been four years since his successful double lung transplant. He does gymnastics post-transplant and maintains a very healthy lifestyle to live it to the fullest. His mantra in life is that with persistence and a positive attitude, one can tread difficult paths. People like him can really change the face of society,

Mountains do not rise without Earthquakes.

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Our Collaborations

Collaboration no 1 - CHRONIC PAIN INDIA

Chronic Pain India is a platform created to bridge the gap between chronic pain, chronic illness warriors, and health professionals. They also create awareness and educate people.

In June 2020, Scleroderma India collaborated with Chronic Pain India to spread awareness about Scleroderma through their Online Platform.

Chronic Pain India Interviewed our trustee, Neetu Wadhwa, and released a video Interview on their Online Platform. The interview not only spoke about our Trustee's journey but also spoke about few takeaways for the fellow patients, which are as follows: -

- Take one day at a time.
- Try to accept situations and your condition, which is the only thing to start healing.
- Stress will be there; adopt strategies to manage stress or take the help of professionals to tone down anxiety from your life.
- Follow up with doctors is a must; listen to them adopt the changes they tell you, inculcate lifestyle changes.
- Don't exert yourself or put too much pressure on yourself. Take rest during the day if needed.
- Make a mantra for yourself. It is ok. I may have a bad day today, but tomorrow will be better.
- A small Exercise regime too can work wonders. If you cannot do exercises, start small with walking for 5-10 minutes, and gradually with the help of experts, you can start exercising. Scleroderma India has collaborated with a Yoga expert who conducts yoga and breathing classes for Scleroderma patients. Take advantage of that.

Our Collaborations

Collaboration No 2 - Meditation Sessions with Yoga for Scleroderma



Phone in, no internet needed

US +1 669 900 6833

Meeting ID: 83716985833

More US and International numbers
<https://us02web.zoom.us/j/83716985833>

Wednesday Wind-down

Free Weekly Guided

Relaxation

Wednesdays

3:00pm CEST

6:30pm India Std Time

9:00pm Taiwan Std Time

Starts July 15, 2020



Join us on Zoom

<https://us02web.zoom.us/j/83716985833>

Yoga for Scleroderma is a Trained group of Yoga Professionals who 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 religious guide, a CD, or even a recording of yourself playing back to you. The guide will instruct you to relax specific muscles in the body until they are comfortable and lead you through mental images and visualizations, often healing light or the dissipation of past wrongs. 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.

Yoga is a way of life for many. Many patients swear by the positive changes and results after including meditation and yoga in their daily life.

These meditations are Led by the trained Instructor from this group and are Online every Wednesday since July 2020.

As a result of these Online Meditation Sessions, many patients have reported decreased stress and increased concentration in their lives. They can focus more on the disease Management aspect of their life.

Our Collaborations

Collaboration No 3 - OSTEM



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.

Scleroderma India collaborated with OSTEM in May 2020 to extend support to their patients during the pandemic. What started as short-term support, extended till date, where OSTEM Professionals –

- Counsel patients 1-1 who require mental health counseling. Many of them do not speak or share on public forums; group members benefit from these counseling sessions.
- Have conducted various webinar sessions to spread awareness about mental health and how best the chronic patients can utilize some tips and techniques to Accept Chronic Conditions, Guide about Coping techniques, etc. Have shared expertise in small groups of Patients Support Group meetings.
- Helped in recording Informational video on - Acceptance of Chronic Disease in a step-by-step process.

Our Collaborations

Collaboration No 4 - Patients Engage



Patients Engage a social enterprise, provides support to patients and caregivers in the management of chronic conditions. In August 2020, Scleroderma India's cofounder - Neetu Wadhwa, along with other Rheumatic Community's Patient Support Group Leaders, participated in a panel discussion around the Impact of Rheumatic Condition on the Body Image and Self Esteem.

The other topics covered by Panellists were:-

1. What is Body Image.
2. How do rheumatic conditions impact patients physically- some examples include hair loss, pigmentation, weight gain, and stretch marks.
3. How these physical changes impact self-esteem and their relationship with the spouse, children, family, colleagues, and friends.
4. Fatigue, inability to plan, withdrawing from social life and Jobs.

Key takeaways were:-

- Acceptance- is the most important aspect; if the acceptance is not there, this disease becomes more difficult.
- Find Purpose- make your hobbies your passion, do whatever makes you happy learn new things. Meet new people. Don't shy away.
- Importance of Exercise-find ways to exercise, do whatever suits your body but make it a part of your life.

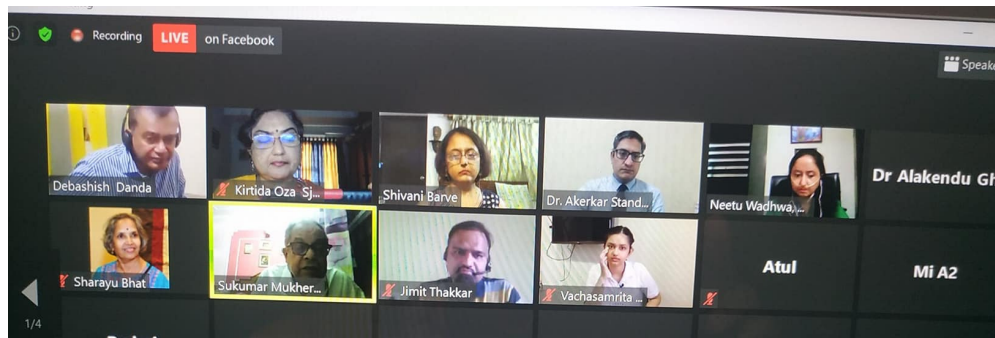
Our Collaborations

Neetu Wadhwa shared how Systemic Sclerosis (SSc) patients suffer a drastic change in their facial features due to the stretching of the skin and the narrowing of the mouth, giving the person a 'mouse-like appearance. The reduced mouth opening also poses challenges in eating, leads to cheek bites, and impedes getting appropriate dental treatment. The skin loses its elasticity and often results in disfigurement of the hands, leading to loss of functionality.

These drastic changes in physical appearance affect the self-esteem of the patient. Hypo-pigmented patches on the skin and hands are another reason for patients to avoid socializing. Patients feel the need to resort to unique make-up to cover the 'blemishes,' adding to the already heavy financial burden due to expensive medication for the disease.

Our Collaborations

Collaboration No 5 - Rheumatic Community



This collaboration happened between Patient Leaders of various Rheumatic Diseases and our Trustee Neetu Wadhwa who spoke on Scleroderma.

Scleroderma - the dictionary meaning is- confined to the skin, so most of the patients who get diagnosed, visit dermatologists. This session throws light on the line of treatment. It also gave information on why alternative treatment is not advised. There is no cure in modern science for scleroderma, but there is enough data for us to know that only Rheumatologists are the specialists to be contacted to treat this disease. There are enough case studies to explain that stopping medicines or going completely towards these treatments has shown negative results.

Resources from nature, Ayurveda, and homeopath have been there for a long time. Still, with time the study patterns have changed, companies to make the medicines cheaper use heavy metals, {there are medical papers to prove that} these have non-reversible effects in certain cases. There is no medical proof to show that these medicines help people in any shape and form.

A thread about Valid sources of information, too, was discussed. Information is very vital in today's day and time, especially if one is suffering from chronic illness; now the question arises for authenticated information, google gives us so many scenarios which can confuse us. We at Scleroderma India have been following these particular resources to develop the specific content for Indian patients.

Our Collaborations

- Scleroderma Foundation US Scleroderma Info
- Scleroderma Patient Intervention Network
- Self-Manage Scleroderma .org
- Clinical trials Registry in the Indian context- <http://ctri.nic.in/>

We develop regional content in various languages to cater to patients from villages/small regions. We also conduct knowledge sessions with experts and professionals for patients and caregivers so that the patient community can get accurate information.

Another Important area that Panelists discussed was Socio-Cultural Issues Related to marriage and Pregnancy. Marriage in the Indian sub-continent is considered very important; this is why some young patients do not want to disclose or talk about their illness, and the understanding is also minimal. The prospective partners google and are afraid to commit. Then comes the question, can we have marital relations? Can a child be conceived? Again instead of taking opinions from doctors, they prefer to come to their own conclusions or google. All these topics were also covered, making this a precious collaboration.

Our Collaborations

Collaboration No 6 - Newz Hook Online Platform

Newz Hook, a prominent platform that spreads awareness on disability, interviewed our trustee Ms. Neetu Wadhwa on her journey. She talks about her journey with the disease and narrates her story.

She spoke about how her fingers started turning blue, she had bronchial issues and started developing acid reflux. She tried alternative medicine, allopathy even went to the extent of changing cities but in vain.

Working as a professional in the IT industry, she started feeling the stress of coping. It was only after 3 years of suffering that she got diagnosed in 2009. She was diagnosed with scleroderma, acid reflux, and interstitial lung disease. This means her gastrointestinal tract and lungs were compromised. In the initial years, she was able to work full-time as an IT professional, but in a few years, she had to give up her job.

She speaks how chronic fatigue became a way of life for her; in 2017, she had to start using oxygen 24x7. She today requires a wheelchair to walk a few steps. She covers the topic of invisible disability and how we have no recognition of this here.

She further speaks about how the conception of the scleroderma India came into being. She had the vision to develop a support group that brings people with the same ailment to come together; she wanted to provide a platform to them and medical know-how and monetary help to the destitute patients.

Our Collaborations

After 5 + years, her dream is taking shape; a group of 150+ patients, collaborations with other platforms are giving her wings to soar higher. Since her diagnosis, her condition is the same but the spirit to fight the disease is not yet over. She believes that what does not break you makes you stronger in Life. She believes in looking for the silver lining in every situation; nothing should be taken for granted in life, and we should enjoy every moment with our loved ones.

Informational Content for Patients

We, at Scleroderma India, strive hard to provide information to all our patients of the disease; we try to take care that language should not be a barrier. We requested various doctors to record videos that are available on our youtube channel.

The various topic on which Videos have been recorded in multiple languages are:-

1. How to Accept a Chronic Illness - Step by step process

2. What is Scleroderma

This covers these questions:-

- What are the Symptoms of scleroderma?
- What are the Risk factors, including the risk of transmission to my child
- What are the Complications of Scleroderma which people face in day to day life
- Which are the tests recommended by doctors to diagnose? If blood tests are negative, can I have scleroderma
- Can you please explain the difference between Limited vs. diffuse scleroderma
- How to treat scleroderma in an ideal way
- Is scleroderma curable
- I feel anxious and depressed. Is it due to scleroderma, and how can I manage it?

3. Medicines and its Myths in Scleroderma

This topic covers these questions:-

- How important are Steroids in the treatment of Autoimmune diseases? I have been taking the Steroids, but I am not comfortable taking them, considering Serious Side effects.
- Does having immunosuppressant medicine mean my immunity is compromised?
- What are the side effects of MMF in the long run?

Informational Content for Patients

- I am scared to take all of these immunosuppressants, acidity tablets, etc., and everything has serious side effects and can cause Liver and Kidney damage.
- Do the medicines only work on the symptoms also help in slowing down/diminishing the effects of scleroderma in our bodies, including restricted mouth opening, non-flexibility in areas such as thighs, stomach, arms, etc.
- How important are Supplements/Multivitamins along with my regular medicines? My doctor has prescribed me some, but they seem too many to me.
- Does homeopathy/ayurvedic treatment go hand in hand with scleroderma treatment?
-
- Is it advised to take flu shots since many of us are on immunosuppressants? Even if I don't get sick that often?
- While taking over-the-counter medicines for sicknesses like fever, headache, nausea, etc., is it advised to continue with the regular medication or stop them for a while?
- Is it okay to take painkillers too often if one is suffering from recurring joint/muscle pains?
- Are cheaper alternatives to a certain medicine of low quality? For example, tadalafil is also available as - tadact by another brand, but at a different price.
- Are injectables better & safer than oral medication in managing scleroderma? What are the advantages or disadvantages of both?

Our Webinar Sessions

Webinar - ART THERAPY

- Art therapy is a specialized area of mental health that uses art materials and the creative process to explore emotions, reduce anxiety, increase self-esteem, and resolve other psychological conflicts.
- Art therapy improves people's mental health who are dealing with anxiety, depression, and much more.
- Art therapy is a calming exercise.
- This particular art therapy was designed especially for Scleroderma Patients, using Water Colours.
- The Art therapist shared with students that the final product is not important, but the creative process is.
- They were not working with particular forms or shapes here and letting the paint do the work. When we let go of the need to impose form, our minds can relax more.
- Using this fluid medium, we stimulate our sensory experience, especially our visual sense. As we watch the colors mix, we might see a reflection of our inner feelings at
- At the same time, we feel soothed.

The takeaway from this session was that sometimes colors release our inner turmoil, which makes us lighter and calmer; it is proven that many times such therapies go a long way in accepting certain situations.

Our Webinar Sessions

WEBINAR - Dental Hygiene

Important Risks to Your Oral Health

General Body:

- Sclerodactyly (tightening of skin and fingers)
- Raynaud's Phenomenon
- GERD

Psychological:

- Depression/Anxiety
- Stress



Four Main Categories:

Teeth/Oral Cavity:

- Xerostomia (dry mouth) → increased risk of cavities, gum disease, candidiasis
- Bone resorption → bone levels are decreased
- Dysgeusia (taste change) → from medications and dry mouth

Extraoral:

- Microstomia (small mouth)
- Muscular Pain or Temporomandibular Pain



Scleroderma India conducted a webinar with Sneha Prem and Allison leader MS BMD 2022 candidates from TUFTS University and Massachusetts UniversityUSA.

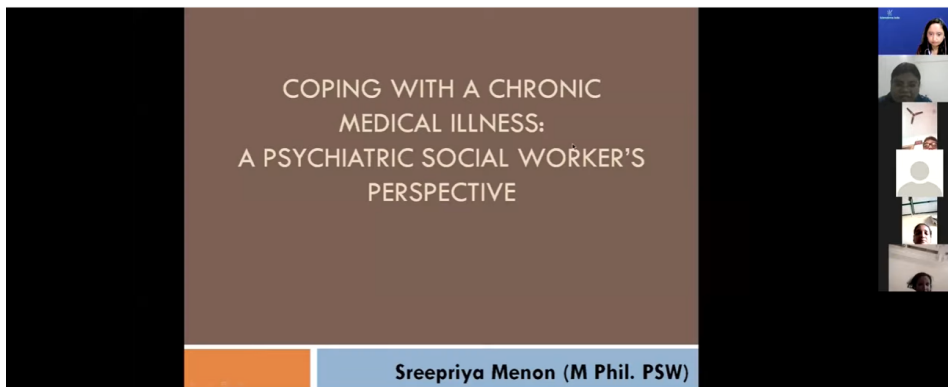
They explained that autoimmune disorder involves the overproduction of collagen, which is a type of protein found everywhere in the body, particularly in the skin. So this results in the classic presentation of skin tightening with a range of severities, and so this skin tightening presentation is particularly evident in the head and neck region. Scleroderma can cause gum disease, which is essentially gum tissue pulling away from the tooth.

Many scleroderma patients develop dental issues because of facial muscle tightening; chewing problems are common, and so are mouth ulcers and dry mouth, which often lead to teeth decaying. They also suggested that dental appointments are a must where the doctor will treat according to the condition. Physiotherapy can help in extreme cases.

They tried to resolve common issues with common remedies. It was a very informative session.

Our Webinar Sessions

WEBINAR - *Hope to Cope with Chronic Illness*



Scleroderma India conducted a webinar about managing mental health with Mental Health Social Worker, Ms. Sreeproya Menon, for chronic illness. Patients with scleroderma become insecure about their looks and have many mood swings.

Skin changes are obvious to people around us. Often, insecurities are ranging from why this happened to me, my fault and many more. This disease has a very complex nature and can really play on one person's mind. No one day is the same as the last one. Professional help at the right time can give clarity, but it helps people manage things better.

Ms. Menon spoke about many issues few were; the sound mind is the key to a sound body, lot many times we google many of our symptoms and start imagining them, at this point is very important to understand that those symptoms are general may or may not be related to you, the mind should be kept calm, which should not start affecting you.

We tried addressing a few such concerns in the session. Ms. SreepriyaMenon helped us with various solutions for thinking positively and dealing with insecurities.

Our Webinar Sessions

WEBINAR - Hope to Manage Raynauds (Blue Fingers)



This webinar was about managing Raynaud's Autoimmune conditions, and this was presented by our esteemed guest Dr. P.D Rath.

About Dr. P.D Rath

Dr. Rath is a Rheumatologist and director with "Max Hospital Delhi". He has always been a supporter of Scleroderma India.

What is Raynaud's phenomenon?

'It is "cold or stress" induced episodic color changes (white or blue) of the skin of the digits of the hands or feet. Raynaud's phenomenon is a problem that causes decreased blood flow to the fingers, ears, toes, knees, nipples, or nose.

What triggers it:-

- Cold Temperature
- Stress
- Smoking
- Vibrating equipment
- Symptoms and Signs: -
- Coldness of fingers
- Discomfort, Pain, and Numbness
- Discolored fingers

The doctor issues basic guidelines to dress warmly, keeping the affected areas covered, and some calcium-channel blockers.

Our Webinar Sessions

WEBINAR - Patient Story of KAVITA CHADHA



Ms. Kavita Chadha is a scleroderma patient with multiple underlying health conditions besides scleroderma. She is battling all of them very beautifully while handling various responsibilities in her life.

Her initial symptoms were high-grade pain in her hands and feet; taking pain killers frequently was not an option because of other underlying medical conditions. Initially diagnosed with high uric acid, she was under medication for many months; when she found no reprieve, she was asked to make an appointment with a Rheumatologist.

In consultation with the rheumatologist and after many investigations, she was diagnosed with Scleroderma. Initial shock led to the array of confusion her treatment with usual steroids and immunosuppressants started. In some months, she started developing a persistent dry cough; on investigations, ILD was diagnosed.

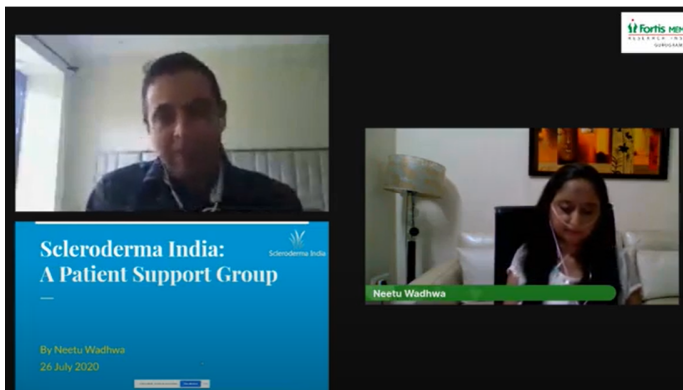
She also had heart surgery in 2001. The Doctor provided some inhalers; it brought certain relief. Kavita speaks about handling all her problems with a salt pin; she took all her problems in her stride and refused to bow.

She is a librarian in an academic institute. She has a school-going daughter and her husband is overseas. She is handling multiple dimensions of her life with calmness and positivity.

Warriors like her are an inspiration.

Our Webinar Sessions

WEBINAR - Lung Complications in Scleroderma



This webinar is all about the complications in Lungs with Scleroderma, and this webinar was presented by “MS. Neetu Wadhwa” and “Dr. Naval Mendiratta.”

Ms. Neetu Wadhwa is a patient of scleroderma and is also one of the co-founders of Scleroderma.

About Dr. Naval Mendiratta:- Dr. Naval Mendiratta is a consultant of Rheumatology at FMRI, Gurgaon.

About the Webinar: This webinar aimed to educate patients about complications and problems resulting from lung issues. The main issues in Scleroderma are lung fibrosis, which reflects the tendency of Scleroderma to cause scarring in the skin of internal organs, and pulmonary arterial hypertension (PAH), which reflects the cardinal proliferate vasculopathy, lung disease is the leading cause of SSc-associated death. In the past few years, strategies for managing the above-said issues have greatly progressed. Clinical trial results support the use of immunosuppression, including high-intensity regimens with autologous stem cell transplantation. Individuals who have a borderline elevation of pulmonary arterial pressure need to be appropriately managed and followed up.

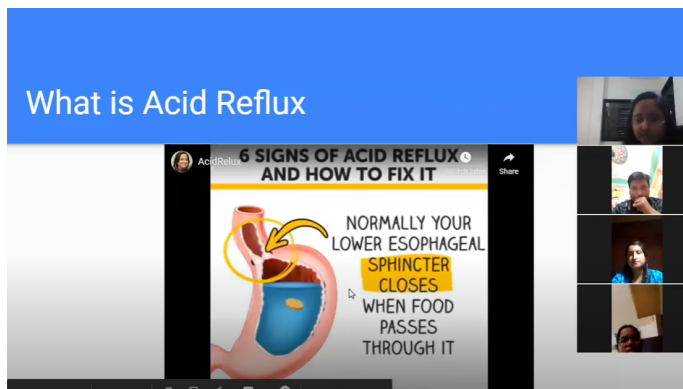
Our Webinar Sessions

Some Major Points

- Lung complications are frequent in systemic sclerosis (SSc) and include lung fibrosis and pulmonary hypertension, which substantially affect disease outcomes and are major causes of SSc-related death.
- Change the way you breathe. Deep breathing or diaphragmatic breathing allow the lungs to inflate and deflate fully, helping to increase lung capacity and get more oxygen into the bloodstream. Multiple licensed therapies exist for pulmonary arterial hypertension, and the use of these agents alone and in combination has improved outcomes and survival.

Our Webinar Sessions

WEBINAR - Acid Reflux Management



This webinar was about Acid reflux management. Ms. Neetu Wadhwa presented this session; She is a co-founder and a patient of Scleroderma, and another patient was also present as a panelist, Mr. Ajit Tolani.

What causes Acid Reflux?

One common cause of acid reflux disease is a stomach abnormality called hiatal hernia. This occurs when the upper part of the stomach and LES move above the diaphragm. Normally, the diaphragm helps keep acid in our stomach. But if you have a hiatal hernia, acid can move up into your esophagus and cause symptoms of acid reflux disease.

Common causes: Eating large meals or lying down right after a meal. Being overweight or obese Eating a heavy meal and lying on your back or bending over at the waist Snacking close to bedtime Eating certain foods such as alcohol carbonated drinks, coffee, or tea, Smoking, pregnancy is the few.

Symptoms of Acid Reflux

Acid reflux can cause an uncomfortable burning feeling in your chest, which can radiate up toward your neck. This feeling is often known as heartburn.

Our Webinar Sessions

If you have acid reflux, you might develop a sour or bitter taste at the back of your mouth. In some cases, GERD can cause difficulty swallowing. It can sometimes lead to breathing problems, like chronic cough or asthma.

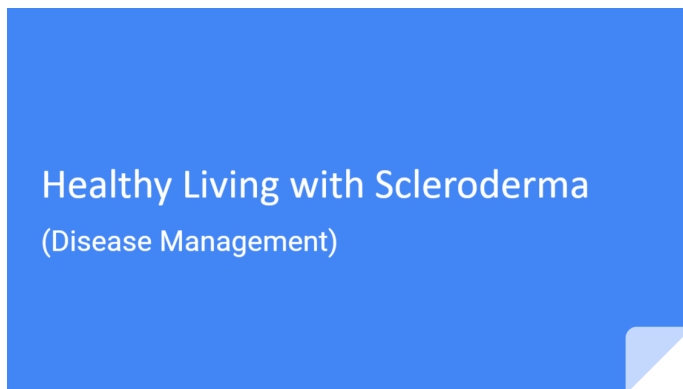
Management of acid reflux - Eat sparingly and slowly. A full stomach can cause more reflux into the esophagus. Eating small meals more frequently rather than three large meals daily. Don't drink carbonated beverages. They make you burp, which sends acid into the esophagus. Drink flat water instead of sparkling water. Stay up after eating. When you are standing or even sitting, gravity alone helps acid in the stomach, where it belongs. Finish eating three hours before you go to bed. This means no naps after lunch and no late suppers or midnight snacks. Avoid vigorous exercise for a couple of hours after eating.

What foods help in acid reflux:- High-fibre foods, Whole grains such as oatmeal, couscous, and brown rice Root vegetables such as sweet potatoes, carrots, and beets. Green vegetables such as asparagus, broccoli, and green beans.

Acid reflux is a prevalent ailment in most patients, and proper care and a good regime can help manage acid reflux.

Our Webinar Sessions

WEBINAR - Disease Management



This session was about how we can live healthy with Scleroderma and take care of ourselves.

Medications for Scleroderma:-

Several drugs are being used, but only a few well-designed studies have been performed. These immunosuppressing drugs include methotrexate, cyclosporine, anti-thymocyte globulin, mycophenolate mofetil, and cyclophosphamide.

Treatments available for Scleroderma:

Getting pain relief through nonsteroidal, anti-inflammatory medications or corticosteroids Easing skin itchiness with skin lotions and moisturizers.

The latest treatment for Scleroderma

IVIG is already used to treat a range of immune-related conditions and may have both immunomodulatory and anti-fibrotic effects in scleroderma

How do you stop scleroderma progression?

No medication can cure or stop the overproduction of collagen that is characteristic of scleroderma. Your doctor may recommend medications to Treat or slow skin changes. Dilate blood vessels. Suppress the immune system. Reduce digestive symptoms. Prevent infections. Relieve pain. Eat food that suits you,

Our Webinar Sessions

Good Mental Health for Scleroderma

Patients with SSc often experience elevated symptoms of psychological distress, determined by changes in physical appearance, pain, fatigue sensation, and difficulty in daily life occupations.

The scleroderma patients reported significantly increased depression and anxiety, somatization, interpersonal sensitivity, and obsessive-compulsiveness.

Having a chronic illness can be very stressful and scary, and not unusual for people with scleroderma to become depressed. Physical activity can help in relieving joint pains and also help with the uplift of the mood.

Our Webinar Sessions

WEBINAR - Breathing Exercises for Chronic Diseases



This breathing exercises webinar was presented by the “Yoga for Scleroderma group,” Which is U.S based. This was the second session in a span of 6 months.

About the Webinar

In this webinar, they spoke about different yoga exercises that can help everyone in one or the other forms.

Full Diaphragmatic Breath

Diaphragmatic breathing, or “belly breathing,” involves fully engaging the stomach, abdominal muscles, and diaphragm when breathing. This means actively pulling the diaphragm down with each inward breath. In this way, diaphragmatic breathing helps the lungs fill more efficiently. Some benefits of deep breathing are: they can act as a natural painkiller, Improves blood flow, improves immunity, Calms down anxiety. Helps you sleep better. Increases energy level, improves posture may help in reducing inflammation.

Alternate nostril breathing

With regular practice, alternate-nostril breathing can bring better balance to your nervous system, and less stress response and activity lit lower blood pressure. Deep breathing and alternate-nostril lower heartbeat blood pressure. It improves breathing.

Our Webinar Sessions

Alternate nostril breathing can also be a form of daily meditation easily practiced as part of your bedtime routine, as a way to rebalance yourself.

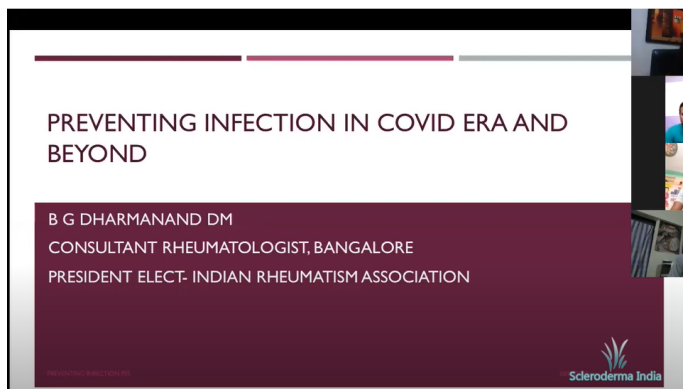
Belly breathing

Sit or lie flat in a comfortable position; put one hand on your belly just below your ribs and the other hand on your chest. Take a deep breath in through your nose, and let your belly push your hand out.

Doing these breathing exercises regularly can give very satisfying results.

Our Webinar Sessions

WEBINAR - Preventing Infections during Covid Era and Beyond



This session was presented by “Dr. B.G Dharamanand.” Dr. B.G Dharamanand is the President-elect of the Indian Rheumatology Association and an eminent member of the Karnataka Rheumatology Association.

About the Webinar: -

The current COVID pandemic has changed the way we look at the world.

Infections And Autoimmune Disease: -

- Infections can be an environmental trigger for AIRD AIRD may themselves predisposed to infections.
- Drugs and immunosuppressive predispose to infections.

Infection Prevention

Vaccination and other measures: -

- Patient education and prompt evaluation and low index for suspecting infections
- Reduce steroid when an infection is suspected
- With the hold immunosuppression
- LTB screening Viral screening Vaccination

Potential Solutions

- Dental hygiene
- Electronic toothbrush
- Physiotherapy
- Non-Drug measures for GERD
- Alginate and promotility drugs

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- Cyclical antibiotic therapy for Sibo
- Preventing digital ulcer
- Vaccinations

Anti- Inflammatory Diet

Some foods contain ingredients that can trigger or worsen inflammation. For example, sugary or processed foods may do this, while fresh, whole foods are less likely to have this effect. An anti-inflammatory diet focuses on fresh fruits and vegetables. Many plant-based foods are good sources of antioxidants. Some foods, however, can trigger reactions that can cause certain infections, so consult a dietary expert in case you feel the need.

Gut Microbiome and Autoimmunity

The gut microbiota can influence or interfere with immunity sensing in discriminating between self and non-self, contributing to autoimmune diseases. Patients with autoimmune diseases commonly display signs of impaired gut barriers, resulting in immune exposure to commensal gut bacteria, resulting in infections; gut infections are prevalent with autoimmune disorders, so care is always required in terms of not developing infections.

The types of vaccinations which are required

- Pneumococcal Vaccines
- Influenza Vaccine
- Hepatitis B
- Zoster Vaccine – Not available yet
- HPV- For young girls
- Minimal risk of the flare of AIRD- Reassuring

Social Distancing/Self Isolation & Other Measures for avoiding infections

- Social distancing all the time
- Hand washing
- Mask

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Strict social distancing

- At home
- At work
- Work from home
- Avoid social visits
- Avoid public transport
- Try telephonic or Video consults.

Conclusion

- Infection is a major cause of morbidity and even mortality
- Multiple causes
- Prevention is always better than cure
- Infection prevention is both physician's and patient's responsibility
- Take the fear away
- Confidently take preventive measures
- Seek medical attention as soon as you suspect infection
- Don't forget humble vitamin D and C

Our Webinar Sessions

WEBINAR - Town Hall Session on Healthy Living with Scleroderma



Scleroderma India conducted a session in Scleroderma Awareness month – June 2020 to give an insight on Scleroderma.

Following were our guests:-

Dr. PD Rath

He is a consultant Rheumatologist associated with “Max Hospital New Delhi.” Sir has more than 15years of experience in the rheumatology field and has successfully treated patients with rheumatic conditions. He was also awarded the best rheumatologist for Delhi N.C.R 2019.

Dr. Manish Gupta

Dr. Manish Gupta is a Physiotherapist in Max hospital in Delhi. He has over 20 years of experience with various hospitals. He and his team provided physiotherapy support for the badminton pre-events for the Delhi commonwealth games in 2010.

Ms. Sreepiya Menon

She works for individuals and families for the betterment of mental health. She has been a part of initiating and organizing - Online social team for all minds.

Ms. Neetu Wadhwa

Patient of scleroderma, co-founder at the Scleroderma India Trist

Our Webinar Sessions

Dr. P. D. Rath:-

Scleroderma is an autoimmune disease.

What is an autoimmune disease? The immune system normally guards against bacteria and viruses. When it senses these foreign invaders, it sends out an army of fighter cells to attack them. Normally, the immune system can tell the difference between foreign cells and your good cells. An autoimmune disorder is when the immune system stops the distinction between good and bad cells.

When the body senses danger from a virus or infection, the immune system kicks into gear and attacks it. This is called an immune response. Sometimes, healthy cells and tissues are caught up in this response, resulting in autoimmune disease. Some autoimmune diseases are more common in certain ethnic groups. The early signs are fatigue, achy muscles, trouble concentrating, numbness, and tingling in the hands and feet. Skin rashes.

How can it affect: In an autoimmune disease, the immune system mistakes part of your body, like your joints or skin, as foreign. It releases proteins called autoantibodies that attack healthy cells. Some autoimmune diseases target only one organ.

Dr. Manish Gupta Advice:-

Physical therapy conducted under the supervision of a physiotherapist can help stretch the skin, muscles, and joints affected by scleroderma using exercise. This can improve posture, increase the range of movements that a patient can perform, and prevent loss of muscle mass and strength. Prevention:- Keep the joints warm – hot water soak or wax bath. Stretch all the joints from the wrist to the last digit

Ms. Sreepriya Menon Advice:-

The disease does not stop you from living a full and productive life. Keeping a strong and positive mindset can take you a long view. It can take months to years to develop the full extent of the disease; symptoms can vary for everyone. Do not google and put the cart before the horse.

Our Webinar Sessions

Ms. Neetu Wadhwa (Patient Story)

She was diagnosed in 2009, but the symptoms were visible from 2006. Her journey for diagnosis included multiple doctor visits, varying symptoms like breathing issues, acid reflux, joint pains, swelling in fingers. Since doctors cannot co-relate symptoms, it took 3 yrs for the final diagnosis. Some doctors even went ahead to suggest that she may have some psychological issues. She had to give up a full-time job when it was challenging for her to manage her symptoms. She was asked to undergo a Scleroderma test. She was referred to a Rheumatologist, from there began her treatment.

About her journey: Her journey is filled with ups and downs. She had to take chemotherapy sessions monthly with high doses of steroids for three years. Her lung and heart condition became severe on different occasions. She was also on bed rest for 1 year each, on both occasions.

Her Advice: A healthy mind makes a tough situation easier.

Our Webinar Sessions

WEBINAR - Yoga poses for Scleroderma



This webinar is all about yoga for Scleroderma patients, and this webinar is presented by some of our esteemed guests: -Ms. Cheryl Albright, Ms. Kathy, and Ms. Alexis Harrison.

Ms. Cheryl Albright has been an educational therapist for the past 17 years and using yoga in her therapy practices. Alexis Harrison was diagnosed with scleroderma in 2014, just shortly after having her daughter, and she met Ms. Cassie at a scleroderma education conference. She ended up getting a yoga certification. Pat Mcmillan is the newest member of the Yoga for Scleroderma team.

A yoga practice designed for scleroderma patients can greatly relieve the symptoms of the disease and provide significant health benefits. Specific poses and sequences may stimulate glands and functioning of the immune system and improve circulation and normalize blood pressure.

How to perform proper yoga for Scleroderma; Listen to your body. Consult a team of professionals. Symptom management comes first. Don't overdo it, be gentle, start slow, and build gradually. Plan your program.

Poses

Chair Pose - Also referred to as "Fierce or Powerful" pose or "Awkward" pose, this pose is most commonly referred to as "Chair pose" since it looks like you're sitting down in a chair. To maintain balance, you can also use a chair or wall for your pose.

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From Mountain Pose, bend your knees to 90 degrees over your ankles, and keep weight equally distributed on your feet. Engage your lower abdominal muscles as you reach your arms up and pull your arm bones back. You can continue working on your feet, providing you with a range of motion, flexion, extension, etc.

How to get up and down from the floor without using your hands, wrists, knees: It is important to have something stable that will not move. You can have a chair with rubber feet that is sitting on a yoga mat. So, this way you can use your chair to support yourself so that you will not move and not fall, which is the most important thing about exercise. So, since you are already on the floor, you will start bringing yourself up to standing and coming back down. You can use your forearms, not your elbows, not your wrists, place your forearms on the chair, and use your feet in the chair as support to come up to standing.

Leg Exercise to strengthen our legs: This is just a simple leg lift that starts with the right leg lifting. Right leg on the floor maintaining straightness as much as possible. In this exercise, you can lift both right or left legs as much as possible. You can do this exercise by sitting on the floor or as well as sitting on a chair.

Breathing Exercise Which Helps in Digestion.

1. Sit or lie in a comfortable place.
2. Place one hand on your chest and one hand on your abdomen.
3. Inhale through your nose for about 4 seconds, feel your abdomen expand.
4. Hold your breath for 2 seconds.
5. Exhale very slowly and steadily through your mouth for about 6 seconds.

It gave many takeaways, the important one being that yoga is important for everyone as it calms the mind and body.



Our Future Plans

Miles to go before I rest; though we have started taking positive steps in our endeavor, we still have a long way to go. However, we have plans to make it a successful platform pan India. We want to reach every corner of the country to help every patient we can.

We are looking for more collaborations that can help our fellow community, and we want to plan more webinars to make the patient more aware of the treatments.

We want to get into the rights of patients to help them get better medical cover. We aim at fighting INVISIBLE DISABILITY. We have plans to help our destitute patients financially as this disease brings anguish and a great financial burden.

The biggest issue is the diagnosis, as it is an overlapping disease; we want to work in this direction with the medical fraternity. In addition, we want to collaborate with pharmaceutical companies for more reasonable drug prices.

We want to collaborate with testing labs to help us moderate prices for destitute patients. Our mission is to take

Our Future Plans

the fight against scleroderma to the next frontier and redefine clinical benchmarks and outcomes.

For patients, we stand for hope and the resolute truth that Scleroderma is sensitive! It also demands innovation and a fresh way of thinking. At Scleroderma India, we believe we can help foster and nurture ideas that will trigger the next wave of brilliance care. Initiatives like the International System Sclerosis Conclave back our vision with action, recharge our agenda with collaborative brilliance.

Together we believe we have what it takes to fulfill our commitment. Here's to a brighter future, a healthier future. For us, the quote from TONY ROBBINS holds, "setting up goals is the first step in turning the invisible into the visible."