IRA E-BULLETTIN

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SUPPORT GROUP

Warriors Not Worriers

“You’re not alone in the world. You’re not alone in your fight.”

About a year back, Doctors in the Department of Clinical Immunology and Rheumatology at St. John’s Hospital, Bangalore in collaboration with Department of Med Social Work brought together a group of Lupus patients and caregivers to set the stepping-stone for Support Group Meetings to be held on the first Saturday of every month.

The goal was to help patients suffering from Lupus, an autoimmune chronic disease, understand and accept the sickness with positivity, and empower them to lead a normal life despite the challenges brought about by the onset of Lupus. What started as a small group of three participants, has now grown to bring together over 50 patients at every meeting. The meetings are now completely run by the patients while the Doctors and Medical Social Workers sit back amazed at the confidence the Support Group has instilled into all the “Lupus Warriors,” as they like to call themselves.

The members at the support groups meetings learn about more aspects of the illness from doctors and other patients who face similar difficulties. A free and comfortable aura surrounds the meetings as patients have started talking openly and honestly about their feelings. Every session, exercises are performed to reduce distress; depression, anxiety, or fatigue and patients are encouraged to brainstorm for solutions to their problems. Nutritionists, psychologists, and dermatologists share their advice, which is made more efficient since it is backed up by experiences and stories shared between patients.Session recaps and stories are updated in the Lupus website accessible to all: website and Instagram page **support_lupus_st.johns**

The biggest strength of support group meetings, however, is the mental comfort, moral courage, and inspiration the patients leave with.

Being a Chronic disease, Lupus treatment is expensive. The Zenith Foundation has sponsored the education for the children of Lupus Patients. St John’s Hospital has subsidized the prices of medication. Companies now donate as part of their CSR. Every bit helps in increasing the financial stability of Lupus Patients.

Over the past meetings, a clear progress has been seen in the positivity and daily routine of all the Lupus Warriors, who have brought together and made the Support Group Meetings a resounding success.

1st Support group meeting: Department of Clinical Immunology and Rheumatology & Department of Medical Social Work, involved in planning of the initiative support group.

(7th Support Group Meeting: Dr. Uttara (psychologist at St. John's Hospital) and Dr. Luke (psychiatrist at St. John's Hospital) interacted with the group on psychological and emotional aspects of dealing with a chronic disease.)

Pondicherry Trip

The journey of a thousand miles begins with a single step.”

The support group led the Lupus Warriors to IRACON 2019 in Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Pondicherry. The support group along with the doctors attended the conference at Pondicherry, which brought together people from all over the country to join hands for the same cause. The conference covered a large range of topics over two days ranging from standard care to breaking down myths about rheumatic diseases. It looked into all aspects including psychosocial counseling and the correct exercise techniques. The end result of the conference was that the patients left knowing that they are not alone in their journey, in fact, Lupus left them with opportunities to meet a wider community and have many more adventures.

Testimonial 1

“As Lupus warriors, we are proud to say that we have started a support group to fill positive thoughts and power to rule over the sickness. With the help of the MSW department and treating team (Department of Clinical Immunology and Rheumatology) we have the freedom live a normal life with Lupus.

Support group meetings help Lupus warriors to understand and accept the sickness. Sharing our experiences provides better understanding on lupus. Doctors from other departments like psychiatry and dermatology are involved in support group which gives us a clear understand about Lupus and informs us about the positive and negative aspects as well as about the Do’s and Don’t.

Our support group led us to IRACON 2019. From our support group with the help of doctors we joined our hands and attended the conference at Pondicherry, which not only enlightened us but helped people from different states join together for the same cause.

We learned be strong, support each other, voice for people who can't speak out, and let the government hear our pain.

Our Support group taught us the importance of medication, exercise, and positive thinking, which are the only ways to live happily.

The group helps us express our joy, happiness, sorrow, pain, vengeance, love, and emotions.

We are looking forward to taking our support group a step ahead and forming an association, which gives us hope and support in all aspects of life.

We feel the support group through us helped us get together. We feel we have got back the days we lost due to Lupus and the confidence is shining out in each one of us.”

- Sujatha

Testimonial 2

“I am very happy to be a member of this group .It has been very beneficial for me.

1. Support group helps us in:

Gaining a sense of empowerment and control

Reducing distress, depression, anxiety, or fatigue

Talking openly and honestly about our feelings.

Financial support

Mental comfortability

2. Few things we learned from support group:

How and from where to get the medicine from low price

The awareness shaped me to adjust with the illness

The importance of diet and nutrition

Benefits of educational assistance & job opportunities

Coping mechanism from support group, which provides us confidence in life to go ahead.”

Testimonial 3

“People from Support groups gain more knowledge about the illness from doctors and other people with the same illness and difficulties. Information on SLE and support from the group gives moral strength to adapt to the situation.

I would like to share one of the incidents that have occurred; my wife needed blood for transfusion and as the hospital didn't have stock they asked me to find a donor. While I was searching for a donor from family and friends, I contacted support group members as well and within a few minutes many people replied with contact details who would donate and a few people came in person to donate blood. This made me to understand the need of support group and the helping nature people have in our group.

Also, the group meetings have been very useful, especially when I got to know about Jan Aushadhi, this reduced drastically on the monthly expenditure on medicines. We are thankful to our doctors for initiating this SLE group, which is helping a lot of people like us.”

Testimonial 4

“I was admitted in 2008 for nearly two months before gradually I started improving thanks to medicine, care, and support of all the doctors, nurses, and family members. Hope is also one of the main things, which help a patient get well soon. Positive thinking, exercise, healthy food, and, of course, timely medicine are a must to live normally. Now I do all the work by myself; after the treatment everything seems to go on well.

I would like to tell all the other friends with SLE to have belief in your doctor and especially in yourself. Now in the end let me kindle your mind and tell you that what you feed your mind will reflect on you. So think positively you are fine, doing very well, and be happy. You will see the changes within yourself.

If you learn to live with SLE, believe me, life is not difficult. Accept the disease like it is like B.P. or diabetes. Make it simple, don't complicate it; doctors are there to control the situation if necessary. Courage is the only thing, which will help you face any problem in life. As we are all smart people we have to support and care for other SLE patients who are in need. Aim is to sow positive thinking in each and every person.

Lupus warriors are proud to say that we have started a support group to fill in positive thoughts and power to rule over the sickness; with the help of the MSW department and doctors we have the freedom to think how we can live a normal life with Lupus. Now we have had meetings to help Lupus warriors understand and accept the sickness first. Each one shares our experiences and we try to find out how others manage it with ease. Doctors from other departments like psychiatry and dermatology also help us understand about Lupus and tell us the things we should surely do and things we should never do...

PSG just joined our hands and attended the conference at Pondicherry, which not only enlightened us but also made all people from different states to join together for the same cause.

Be strong, support each other, voice for people who can't speak out and let the government hear our plea. Now our warriors have learnt medicine, exercise, and positive thinking is the only way to live happily and there is no other way.

Talking to each other we feel the sense of love and belonging among us...

We are working on the trust and feel we are doing a great job in helping ourselves. We have got back the days we lost due to Lupus and the confidence is shining out in each one of us. We are all happy to be a part of the SLE support group."

Testimonial 5

"According to me these are the benefits of the Lupus Support Group:

Support group is creating the link between the like-minded people who are diagnosed with SLE.

It provides the moral support among the support group members.

It gives us psychological strength to overcome the hurdles.

It gives us ideas to overcome the physical difficulties.

It creates awareness on various issues related to medication and procuring it at a cheaper cost, insurance related queries and other aspects.

It provides support for education to patients and their children, insurance, vocational rehabilitation, and group therapy.

Invites multidisciplinary team for better understanding on illness and education on coping skills and strategies.

This support group gives me more confidence to live a better quality of life."

Testimonial 6

"I am Swathi, a 17-year–old lupus patient suffering from these diseases for the past four years now. In the (SJMCH) Hospital, I'm being treated at the Immunology Department. I am continuing treatment and would like to thank for all the help and support. I'm much better now both physically and mentally.

Core Lupus Support Group helps us with every information about dealing with Lupus and supports us. It provides help to every patient and information regarding availing low-cost medication (Jana Aushadi).

We went to Pondicherry for a meeting where we learnt a lot from doctors and patients from many states. We got some points from SLE patients on what was important.

We saw a video about a patient who was suffering from Neuro disease, which was very inspiring.

The video inspires all in every condition & how to overcome the disease successfully.

I thank this group for every support to me.

Thank you so much.”

- Swathi

Testimonial 7

“The essence and compassion that I have developed for St. John's Medical College and Hospital started when I had a stroke in the year 2015.

My Doctor, an Angel-In-Disguise (this is how I want to emphasize in writing on Dr's support).

The Doctors, Nurses and Employees at the Hospital, as well as Volunteers in the SLE Support Group are unique and very humanistic. I myself have experienced personalized patient-centered care.

This further reinforces and reminds me that I, as a patient, belong to an organization whose main goal is to sincerely care, heal people, and to provide comfort to the patient's family members.”

- Sajitha Panicker

“Dream it. Wish it. Do it.”

Over the past year and a half, as I’ve volunteered at St John’s Hospital, I have witnessed a strong and determined group of people who despite suffering from Lupus have decided to take the disease head on. I am amazed at the resilience shown by the Lupus Warriors as they persist to leave a mark on this world despite the struggle they go through in their daily lives. It has inspired me to think bigger and made me accept the world with a whole heart. This past year has made me see the world from a different side and made me realise how petty our problems are in comparision. The Lupus warriors have inspired me with their stories; I hope to make their journey a little more joyful. While a lot of work has been done, aspects of Health & Nutrition, Finances, and Self-Reliance have some way to go. Here is looking forward to more resources to make all of these possible for the Lupus Warriors in 2020.

LET'S
BEAT LUPUS

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