

ANNUAL REPORT FY2018-19

1 August 2019

Abstract

In the seventh year of service in Singapore, we continued to create awareness amongst the public, educate patients and their family members about Crohn's disease and Ulcerative colitis. With generous support from Rotary, we were able to launch a separate Support Group for children with IBD as well as Art Therapy Sessions for parents of these children. By participating as a panelist at various forums, CCSS has advocated on behalf of IBD Patients. Moreover, we have played a significant role in the recently formed Asia Pacific IBD Alliance as well as the Conference organized by the Asian Organization for Crohn's & Colitis (AOCC).

BACKGROUND

On 18 May 2012, the Crohn's & Colitis Society of Singapore was established and recognized as an entity by the Registry of Societies. Ten dedicated volunteers from Rotary clubs had stepped forward to initiate the organization to support patients in Singapore who were diagnosed with Inflammatory Bowel Disease (IBD). Crohn's disease and Ulcerative colitis are the most common types of IBD. Subsequently, on 14 January 2014, the Ministry of Health (MOH) granted Charity Status (Registration Number T12SS0090L) to the Crohn's & Colitis Society of Singapore.

OUR EXECUTIVE COMMITTEE



KEY OFFICE BEARERS

President	Nidhi Swarup
Vice President	Uttam Kripalani
Honorary Treasurer	Kaka Singh
Honorary Secretary	Patrick Lim

OUR VISION

To support persons with Crohn's disease, Ulcerative colitis and related health conditions

OUR MISSION

To create a seamless patient support system that improves the quality of life of patients diagnosed with Crohn's Disease, Ulcerative Colitis and related health conditions with a focus on four key areas:

- Patient Support Groups
- Public Education & Awareness
- Advocacy
- Promoting Research

PATIENT SUPPORT GROUP

Periodic patient gatherings are the backbone of our charity's work and we are driven by the positive feedback provided by various stakeholders. Owing to emotional issues being handled by peer-support i.e. support provided by IBD patients, the healthcare professionals like gastroenterologists and nurses are able to focus on the medical attention needed by each patient. On our part, we invite expert speakers to share their knowledge to equip patients with skills to better manage their illness.

During the year 2018-19 membership increased to 156 members of whom 46 are children. This year we organized eight Support Group Meetings where on an average 20 patients benefitted. There are some patients who have the severe form of IBD and are busy coping with their repeated hospitalizations. Owing to this, they are unable to attend our regular meetings. We have visited some patients during their stay in the hospital to extend our emotional support. Our charity has continued with serving patients by moderating a WhatsApp group. Instead of waiting for physical meetings, this application connects patients on a daily basis to encourage positive thinking. Moreover, when one patient faces a new challenge others provide suggestions to manage it. During the year we saw an increase in numbers from 110 to 124 patients in the WhatsApp group.

IBD PATIENT SUPPORT GROUP MEETINGS

S. No.	DATE	TOPIC
1	22-Sep-18	INTRODUCTION TO RUMMIKUB: WELLNESS SESSION BY ROTARY CLUB OF BUKIT TIMAH
2	27-Oct-18	FOCUS GROUP DISCUSSION: NEW APP FOR IBD PATIENTS
3	24-Nov-18	ART THERAPY (SESSION I)FOR PARENTS OF CHILDREN WITH IBD: Conducted by a Counsellor/Art Therapist: Understanding Myself, My Child/Teen & Impact of the Illness
4	26-Jan-19	COOKBOOK FOR IBD PATIENTS: PLANNING
5	23-Feb-19	ROTARY FAMILY DAY: CCSS SET-UP A BOOTH FOR OUTREACH TO THE PUBLIC
6	23-Feb-19	ART THERAPY (SESSION II)FOR PARENTS OF CHILDREN WITH IBD
7	23-Mar-19	BRIEFING ON ASIA PACIFIC IBD ALLIANCE MTG IN BANGKOK; IBD MONITORING FUND DISBURSEMENTS
8	20-Apr-19	DIET FOR IBD PATIENTS: Speaker, Naturopath Nutritionist, Herbalist and Iridologist
9	18-May-19	7th ANNUAL IBD PUBLIC AWARENESS SEMINAR

Annual IBD Public Awareness Seminar 2019

This year, we celebrated the 7th Anniversary of the Crohn's & Colitis Society of Singapore by organizing the IBD Public Awareness Seminar on Saturday, 18th May 2019 at Holiday Inn Singapore Orchard City Centre. We had more than 80 registered attendees. Volunteers from Rotaract Clubs and the Rotary Club of Raffles City led by President Brian Tan played a key role in organizing a successful IBD Public Awareness Walk.

After a sumptuous lunch, we had the Walk with almost all the seminar attendees participating enthusiastically. Ms. Chee Pei Ling, a CCSS member designed the slogan, 'Life takes Guts' that was incorporated in the T-shirts worn by all participants. One of the three groups opted for a shorter route to Takashimaya and the other two opted for the longer one to Ion Orchard. Dr. Sorinder Singh from the Rotary Club of Raffles City volunteered his professional services as the Doctor-on-call. Ms. Rytha Lew, Past District 3310 Rotaract Representative invested numerous hours to help obtain the necessary Police Permits and approval from Singapore Tourism Board for the IBD Awareness Walk, the Seminar talks as well as for the distribution of Information Sheets on Crohn's disease and Ulcerative colitis. A team of her fellow Rotaractors helped lead the groups during the walk in order to maintain time and safety of the patients. An Ambulance Service was also on standby and fortunately it was not used. Owing to good weather all participants had an enjoyable after-lunch walk along Orchard Road to create IBD awareness.

After an opening speech by Mrs. Nidhi Swarup, President CCSS, we had a patient sharing session by our member Mr. Billy Tan about his tortuous journey with Ulcerative Colitis and achieving remission now. We had three IBD Specialist Gastroenterologists speaking about Crohn's disease and Ulcerative colitis in children and adult patients. They were Dr Shim Hang Hock from SGH, Dr Michelle Gowans and Prof Marion Aw from NUH, followed with a Q & A Session. Many members stayed back to ask our speakers more questions.

We have received some very encouraging remarks from the participants. We wish to record a vote of thanks to the dedicated and enthusiastic volunteers from the Rotary Club of Raffles City, Rotaract Club of Raffles City, Rotaract Club of Chua Chu Kang, Takeda, Ferring, Medtronic and DCH Auriga, for their help and contributions to make this annual seminar a great success!

PARTICIPATION IN EVENTS ORGANIZED BY OTHER ORGANIZATIONS

1	20-Jun-18	IQVIA Q2 ACCESS FORUM: PATIENT ACCESS PROGRAMS IN A WORLD OF HTA	IQVIA
2	24-Jul-18	SOCIAL SERVICE SUMMIT 2018	NCSS
3	July-Aug-18	SINGAPORE GARDEN FESTIVAL	NCSS, GARDENS BY THE BAY
4	11-Oct-18	IQVIA HEALTHCARE SUMMIT 2018: HUMAN SCIENCE MEETS DATA SCIENCE	IQVIA
5	21-Nov-18	IQVIA Q4 MEDICAL AFFAIRS FORUM: DISSECTING THE 'VALUE' IN VALUE-BASED MEDICINE: WHOM DOES IT BENEFIT THE MOST?	IQVIA
6	10-Jan-19	NCSS APPRECIATION NIGHT: CELEBRATING SOCIAL SERVICE TRIBE JOURNEY	NCSS
7	28 Feb & 1 Mar-19	ASIA-PACIFIC IBD ALLIANCE MEETING, BANGKOK	JANSSEN
8	14-17 June'19	ASIAN ORGANIZATION FOR CROHN'S & COLITIS CONFERENCE 2019, TAIPEI	AOCC

FINANCIAL ASSISTANCE

CHILDREN'S ASSISTANCE FUND was set-up in 2014 to reduce the financial burden on families of children with IBD. Generally, children with IBD are seen by Pediatric Gastroenterologists at KKH and NUH. The families' situation is assessed by Medical Social Workers at the hospital. Subsequent to this initial period of no food, a child is permitted to start taking some food and can continue Modulen as a supplement.

Our charity purchases ModulenIBD in bulk and passes the entire 30% discount to patients. We learnt from Medical Social Workers (MSW) that some families needed more help. For the benefit of **families in need**

of 100% assistance, Modulen is provided free-of-charge for up to eight weeks. All assessment is undertaken by our partners in service, the MSW at various hospitals. We are grateful to Rotary Club of Raffles City for the continued donations and Emtech Wellness International PL for voluntary support with storage and distribution of Modulen.

IBD MONITORING FUND Owing to our public education efforts, more supporters of CCSS are familiar with the financial burden faced by families of IBD Patients. Donors have been briefed about the high costs associated with outpatient treatment of IBD. As most patients do not have an insurance policy to cover such expenses, they need to pay out of their own pockets.

While there are schemes in place for those from low-income families and IBD patients from high-income brackets are able to manage on their own. It is the patient from the middle-income bracket who is left to make ends meet. By providing \$600 per year, CCSS hopes to subsidize the cost of blood tests, X-rays, CT Scans, Ultrasound, Colonoscopy or Endoscopy prescribed by the attending specialist. Launched in FY 2014-15 we are continuing to assist the 'sandwich' class based on per capita Income.

CCSS regularly reminds patients about the importance of compliance to doctors' prescribed dosage of medication. Although compliance doesn't provide a guarantee of remission, at least during any given year, the number of episodes of a flare-up of symptoms can be reduced.

SINCERE APPRECIATION

Gastroenterologists play a significant role in introducing the Crohn's & Colitis Society of Singapore to IBD patients. We are thankful to our **Panel of Medical Advisors**, Dr Ling Khoon Lin from Mt Elizabeth Hospital, Dr Christina Ong from KK Hospital, Dr David Ong and Dr Marion Aw from National University Hospital for their invaluable voluntary contributions throughout the year. We also register our gratitude to Gastroenterologists Dr Lim Wee Chian, from Tan Tock Seng Hospital, Dr Shim Hang Hock from Singapore General Hospital and Dr Malcolm Tan from Changi General Hospital who have kindly continued to serve on our Panel of Medical Advisors.

Owing to Educational Grants from pharmaceutical companies many of our patient education and awareness initiatives have been possible. We thank our corporate partners IQVIA, Johnson & Johnson, Takeda, AbbVie, Medtronic, Ferring and DCH Auriga for their generous support during the year. Without

voluntary contributions from our Medical Specialists and subsidized rental rates of premises provided by the Foundation of Rotary Clubs (S) Ltd, achieving so much in a year would have been quite challenging for us. The kind support provided to IBD Patients by NCSS is also much appreciated. For the newly launched Children's Programme, we are grateful for the generous contribution received from the Rotary Club of Raffles City. On behalf of our beneficiaries and EXCO Members, I take this opportunity to thank all our donors, sponsors and volunteers for their invaluable support.

FUTURE PLANS

- New initiatives are planned to reach out to newly diagnosed patients across various hospitals.
- Support Group Meetings shall continue to be organized periodically for the benefit of IBD patients and their family members. CCSS will build on its current vibrant membership to invite more IBD patients to join the group where everyone is willing to learn, exchange ideas and feel empowered.
- Dedicated volunteers will be engaged in planning and implementation of periodic activities for children with Crohn's disease or Ulcerative colitis.
- All IBD Patients will be encouraged to participate in surveys and research studies.
- Pan-Asia IBD Registry will be initiated by Crohn's & Colitis Society of Singapore in partnership with IBD Specialists from the region.

The past seven years of service has been a rewarding journey for me and I thank all our well-wishers and donors for their kind support and encouragement. I would like to register my sincere appreciation to the entire team of excellent volunteers who have been serving tirelessly on the Executive Committee.



Nidhi Swarup (Mrs.)
President

PICTURE GALLERY: FY2018-19



CROHN'S & COLITIS
SOCIETY OF SINGAPORE

IBD PATIENTS' SUPPORT GROUP MEETING

YOU ARE INVITED TO A WELLNESS SESSION WITH US

SATURDAY, 22 SEPTEMBER 2018
133 New Bridge Road, Chinatown Point #04-10 (TR1)
Singapore 059413

PROGRAMME
2pm-2.45pm An introduction to Rummikub to promote Mental Wellness, courtesy of Rotary Club of Bukit Timah
2.45pm-3pm Refreshments Break
3pm-4pm Patients' Sharing Session

RSVP by 18 Sept. 9756 4066



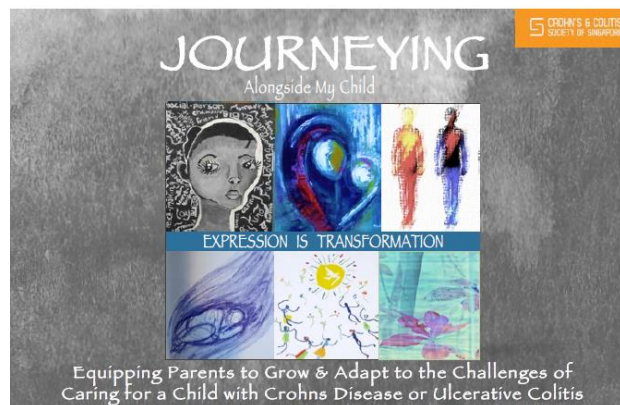
CROHN'S & COLITIS
SOCIETY OF SINGAPORE

IBD Patients' Support Group Meeting

DATE Sat., 27 Oct 2018
TIME 2pm - 4pm
VENUE 133 New Bridge Road, Chinatown Point #04-10 (TR1)
Singapore 059413

PROGRAMME
2pm-2.45pm a NEW App is being developed for IBD Patients. Provide your valuable views and input!
2.45pm-3pm Tea Break
3pm-4pm Patients' Sharing Session

RSVP by 24 Oct. 9756 4066



JOURNEYING
Alongside My Child

EXPRESSION IS TRANSFORMATION

Equipping Parents to Grow & Adapt to the Challenges of Caring for a Child with Crohns Disease or Ulcerative Colitis

A Series of 6 Art Therapy Group Workshops to Examine & Build Caregiving Skills

Explored through : Attachment, Human Development, Neuroscience, Chronic Illness, Grief & Loss, Medical Art Therapy & Child/Adolescent Psychotherapy. Art psychotherapy is an expressive, integrative therapy used in this workshop to enhance caregiving from psychodynamic, socio-emotional, cognitive behavioural & relational aspects

Session Series Topics:

1. 'Understanding Myself, My Child/Teen & Impact of the Illness' (Nov'18)
2. 'Improving Communication with My Child/Adolescent' (Jan'19)
3. 'Emotional Regulation & Coaching' (Mar'19)
4. 'Understanding & Managing Stress (Mine & My Child's)' (June'19)
5. 'Building Resources & Resilience in My Child' (Aug'19)
6. 'Finding Hope & Meaning and a Way into the Future' (Oct'19)

NO PREVIOUS ART EXPERIENCE or ABILITY REQUIRED.
FACILITATED BY A REGISTERED ART PSYCHOTHERAPIST

SESSION 1 – 'Understanding Self, Child & Impact of Illness'

Date: Sat, 24 Nov '18 Time: 2 – 4pm

Fee: Only \$10 per participant (Workshop subsidised by CCSS)

Venue: 133 New Bridge Road, Chinatown Point, 04-10 (TR1) S059413

Register: Latest by 21 Nov'18 (Limited Places Available) Phone: 97564066
Continued overleaf...



RECIPE BOOK
COOKING WITH LOVE

CROHN'S & COLITIS
SOCIETY OF SINGAPORE

IBD PATIENT SUPPORT GROUP MEETING

Let's meet and share ideas to help each other with recipes that work for IBD Patients. Be part of creating our very own cookbook that contains Chinese, Malay, Indian, Eurasian and other recipes we could use any day that we want to!!

IBD Monitoring Fund Disbursement – An Executive Committee Member will present Cheques to a few members. Contact us if you'd like to know more.

DATE SAT., 26 JAN 2018 TIME 2 pm - 4 pm

VENUE 133 NEW BRIDGE ROAD, CHINATOWN POINT #04-02 (MPH) SINGAPORE 059413

A Singaporean Cookbook especially for IBD Patients

Your name will be included with the published recipe

Children can enjoy their meals too... so what if we have IBD?

Over the next few months, take high resolution pictures for our own cookbook

Be part of this yummy journey, see you!!

WhatsApp or SMS

9756 4066 (hp)

RSVP by 20 Jan 2019



**You're invited to our
IBD Patient Support Group Meeting**
March 23, 2019 2pm-4pm

PROGRAM

- o Meet other patients diagnosed with Crohn's disease or Ulcerative colitis
- o Briefing on recent Asia Pacific IBD Alliance Meeting in Bangkok
- o Exchange tips on Management of Inflammatory Bowel Diseases (IBD)
 - o IBD Monitoring Fund Disbursements

133 New Bridge Road, Chinatown Point #04-02 (MPH) Singapore 059413
RSVP by March 20 Email info@ibd.org.sg sms/WhatsApp 9756 4066



CROHN'S & COLITIS
SOCIETY OF SINGAPORE

IBD PATIENT SUPPORT GROUP MEETING
INFLAMMATION & ANTIOXIDANTS

DAY & DATE SAT., 20 APRIL 2019
TIME 3.45PM - 5.45PM
ADDRESS 133 NEW BRIDGE ROAD, CHINATOWN
POINT, #04-10 (TR1) SINGAPORE 059413

Most patients diagnosed with Crohn's disease or Ulcerative colitis ask questions about their diet and how some changes might be able to help reduce some symptoms associated with Inflammatory Bowel Disease (IBD). Medical treatment and knowing your trigger foods are important.

Here is an opportunity for you and your family members to learn something from Ms. Ketki Vinayachandran, a Naturopath Nutritionist, Herbalist and Iridologist. Register today!

FOR MORE INFORMATION CONTACT: CCSS @ 9756 4066 (TEL., WHATSAPP OR SMS)

**7th Annual IBD
Public Awareness
Seminar 2019**

DATE 18 May 2019 (Saturday)
TIME 12.45 PM - 5:00 PM
VENUE Holiday Inn Singapore, Orchard City Centre
11 Cavenagh Road Singapore 229616

Presented by: **CROHN'S & COLITIS**
SOCIETY OF SINGAPORE

Sponsored by: **Takeda**

Supported by: **FERRING** PHARMACEUTICALS, **Medtronic**, **AURIGA**

REGISTRATION CLOSING ON 15 MAY
Full Name, E-mail & Tel no.
E-mail info@ibd.org.sg
SMS 9756 4066

PROGRAMME

- 12:45PM-1:30PM: LUNCH & REGISTRATION
1:30PM-3:00PM: **IBD AWARENESS WALK**
3:00PM-3:15PM: CROHN'S & COLITIS SOCIETY OF SINGAPORE
UPDATES - Mrs. Nidhi Swarup, Founder & President
3:15PM-3:35PM: PATIENTS' SHARING
3:35PM-3:55PM



**TREATING TO TARGET IN IBD - WHAT DOES
IT MEAN TO ME AS A PATIENT?**
Dr Shim Hang Hock

Consultant, Department of Gastroenterology and Hepatology
Director, Inflammatory Bowel Disease Centre
Singapore General Hospital

3:55PM-4:15PM



IBD BEYOND THE GUT
Dr Michelle Gowans

Consultant and Undergraduate Education Director
Division of Gastroenterology and Hepatology
National University Hospital Singapore

4:15PM-4:35PM



**IBD - IMPLICATIONS FOR THE GROWING
CHILD**
Dr Marion Aw

Associate Professor, National University of Singapore
Senior Consultant, Division of Paediatric Gastroenterology
National University Hospital Singapore

- 4:35 PM-4:55 PM: Q & A Session
4:55 PM-5:00 PM: Tokens of Appreciation

I. CROHN'S DISEASE & ULCERATIVE COLITIS PUBLIC AWARENESS EVENTS



1 CCSS BOOTH @ROTARY FAMILY DAY 2019



2 IBD CENTRE FOR EXCELLENCE CONFERENCE



3 SEVENTH ANNUAL IBD PUBLIC AWARENESS SEMINAR MAY 2019



4 ADVISOR VINCENT CHEN WITH IBD PATIENT VOLUNTEERS



5 IBD PUBLIC AWARENESS WALK ON ORCHARD ROAD MAY 2019

II. IBD PATIENT SUPPORT GROUP MEETINGS



6 MEMBERS LOOKING FORWARD TO A TALK ON SPECIFIC CARBOHYDRATE DIET



7 EXCELLENT FELLOWSHIP AMONGST MEMBERS



8 FOCUS GROUP DISCUSSION ON AN APP FOR IBD PATIENTS



9 MENTAL WELLNESS WORKSHOP BY ROTARY CLUB OF BUKIT TIMAH: A SESSION OF 'RUMMIKUB'



10 IBD MONITORING FUND BENEFICIARIES

III. ASIA-PACIFIC INFLAMMATORY BOWEL DISEASE (IBD) EVENTS



11 SECOND ASIA-PACIFIC IBD ALLIANCE MEETING IN BANGKOK 2019



12 RUN FOR LIFE, RUN FOR IBD 1.6KM

We couldn't achieve all these without the invaluable contributions of our expert volunteers, thank you!