

ANNUAL REPORT FY2017-18

1 July 2018

Abstract

In the sixth 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 organized a symposium on Chromoendoscopy for 100 Gastroenterologists from the region. Moreover, we have been able to reach out to IBD Patients in the region leading to the formation of support groups in Thailand, Philippines and Bangladesh in the near future.

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 Secretary	Patrick Lim
Honorary Treasurer	Kaka Singh

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 provided by IBD patients, gastroenterologists and nurses are able to focus on the medical attention needed by each patient. On our part to make the gatherings interesting, we invite expert speakers to share their knowledge to equip patients with skills to better manage their illness. Going by feedback provided by parents of children with IBD, we have continued to organize combined meetings where adult patients, pediatric patients as well as their parents are able to share their experiences in one united group. As we grow in patient numbers, we are looking into developing a separate group for children.



¹ TOKEN OF APPRECIATION FOR OUR SPEAKER, TANIA MARTIN-ACHARD

During the year 2017-18 membership increased to 136 of who 55 are children. This year we organized six Support Group Meetings and IBD Awareness Seminars where anywhere from 20-80 patients benefitted. Talks ranged from Navigating IBD & Diet to CCSS Assistance Schemes, Focus Group Discussions to Calligraphy for IBD Patients. Owing to the close working relationship between Medical Social Workers (MSW) of various

hospitals and our charity, they have continued to encourage patients to join CCSS and the benefits of participation in our gatherings.



2 CHINESE NEW YEAR GATHERING

3 EXCELLENT CALLIGRAPHY BY MR. NG BOON TEE

There are some patients who have the severe form 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 81 last year to 110 patients in the WhatsApp group with strong bonding. It's unfortunate that those patients without a smart phone are left out and we can only stay connected via a phone call, email or during our monthly meetings.

IBD PUBLIC AWARENESS & PATIENT SUPPORT GROUP MEETINGS

S.NO.	DATE	TOPIC	ATTENDEES
1	7 Oct 2017	Children's Power Group: Focus Group Discussion	20
2	10 Mar 2018	Navigating IBD & Diet; CNY Celebration & Calligraphy	28
3	21 April 2018	LIVE Fb Event	21
4	5 May 2018	"Gut & Me": CCSS Booth	400
5	12 May 2018	Optimizing Endoscopy in IBD Patients	120
6	19 May 2018	6 th Annual Patient Education & Public Awareness Seminar	80

PUBLIC EDUCATION & AWARENESS

In September 2017, our President was invited to speak at Leadership Conference in Bangkok. Organized by Takeda Pharmaceuticals, Mrs. Nidhi Swarup shared a patient's perspective of IBD. The event was attended by about 300 Senior Management from around 130 countries. The interview style sharing was very well received and was followed by an equally engaging Q & A session.

Our President used the opportunity to meet with Dr Sathaporn, an IBD Specialist at Siriraj Hospital and a patient to share the importance of an organization that focusses on IBD and to share the print materials developed by CCSS. She also connected them with members of a Rotary Club in Bangkok to encourage them to initiate a Patient Support Group for IBD Patients in Thailand.



4 PRESIDENT NIDHI SWARUP BEING INTERVIEWED IN BANGKOK

Rotary Club of Raffles City in partnership with the Foundation of Rotary Clubs (S) Ltd organized a Charity Film Show, *Star Wars: The Last Jedi* at Shaw Theatres on 18 Dec 2017 to raise funds for a separate Support Group for Children of the Crohn's & Colitis Society of Singapore. The audience were provided brochures about our charity. Moreover, President Kesavapany shared additional information with the audience about the support services provided by the Crohn's & Colitis Society of Singapore. \$15,000 are needed to initiate the Children's Power Group.

The proposed programme has Individual and family counselling sessions, skills training workshops, interest based activities for children and youth, caregivers' training workshops and hospital visits. We are firstly thankful to the Board of Directors, Rotary Club of Raffles City for their enthusiasm, kindness and continued support to CCSS. We are also thankful to AbbVie, Takeda, DCH Auriga and Singapore Totalisator Board for their generous donations towards our new initiative.

In line with IBS Awareness Month and World IBD Day, on 5th May 2018 a forum titled, "Gut & Me" was organized by DCH Auriga at Singapore General Hospital Academia. CCSS was invited to set-up a booth. Our Corporate Video was played on a laptop at the booth. A group of our dedicated patient volunteers and Executive Committee Members distributed the newly updated brochures to the 400 participants. Moreover, two roll-up banners were also printed and displayed for creating a stronger presence.



5 L-R: ROSIE, PAVITAR, NIDHI, WAYNE, BOON TEE



6 VOLUNTEERS AT CCSS BOOTH: "GUT & ME"

As part of our plan to organize *Annual IBD Public Awareness Seminar*, we invited various stakeholders for a half day seminar on 19 May 2018 at Mount Elizabeth Hospital, Orchard. With prominent practitioners from various leading hospitals like Singapore General Hospital, KK Hospital, Tan Tock Seng Hospital and National University Hospital, a total of 80 participants benefitted from the sharing of Patient Experiences as well as Medical Knowledge shared by the IBD specialists.

Thanks to sponsorship of the seminar venue by Mt. Elizabeth Hospital. We are thankful to Takeda for kindly sponsoring all the other event expenses. Last but not the least, the generous goody bags by DCH Auriga added to the event's success and was very well received. Participants had ample time to know other IBD patients, CCSS EXCO members as well as medical practitioners.



7 VP UTTAM KRIPALANI

9 DR LIN HUIYU, TTSH



REGISTRATION DESK; NETWORKING AMONGST PATIENTS



10 EDUCATIONAL TALKS BY EXPERTS FROM NUH, KKH & SGH

PROMOTING RESEARCH

Owing to the pressing need to undertake research studies focusing on Asians, discussions were held in 2016 with Medical Specialists of leading hospitals in Singapore. Subsequently, a two-year project titled, "Optimising Quality of Endoscopy in Inflammatory Bowel Disease (IBD)", by Duke-NUS Medical School was adopted.



11 L-R HENRY, KAKA, BOON TEE, CORINA, NIDHI, PATRICK, TREVINA

Thanks to very generous funding from Rotary Club of Raffles City and the Rotary Foundation, a symposium for 100 Gastroenterologists was held on 12 May 2018.

Participants came to Singapore from nine Asian Countries (Myanmar, Malaysia, Thailand, Indonesia, Brunei, Vietnam, Cambodia, Philippines and Hong Kong) to learn from

experts on the topic of Chromoendoscopy. The six faculty members were led by Dr Roy Soetikno and Dr Tonya



12 KEY OPINION LEADER: DR ROY SOETIKNO

Kaltenbach from USA.

Chromoendoscopy is a technique that doesn't require any new equipment but the use of a dye during colonoscopy and 10 additional minutes for a Gastroenterologist to detect colo-rectal cancer at a very early stage. Unfortunately, it is not part of standard practice for 'at-risk IBD patients' across Asia.

Over the next two years, IBD Patients in Singapore and Hong Kong will also be educated about the benefits of this technique and to encourage patients to participate in the two-year project to be undertaken across leading hospitals in Singapore. Owing to Chromoendoscopy, those flat cells in the intestines that are cancerous can be removed thereby preventing colo-rectal cancer.

President Nidhi Swarup represented CCSS at the symposium and during her presentation spoke about the objective of setting-up the Crohn's & Colitis Society of Singapore, the need for Asian countries to undertake IBD research, role of Rotary in initiating CCSS and its continued support through professionals serving on the Executive Committee, the spectrum of services provided to IBD patients and in the sponsorship of this symposium owing to Rotary International's Global Grant. She also emphasized the need for IBD Specialists to partner with patient groups in order to enhance clinical research, various studies and provision of healthcare in their respective countries.

A booth was also set-up to showcase the vital role of the Crohn's & Colitis Society of Singapore. Dedicated volunteers from Rotary and CCSS were present at the booth to distribute brochures and share information with various participants. Roll-up banners enhanced the image of CCSS during the symposium.

ADVOCACY

On 20 June 2018, our President was one of the panelists at a forum organized by IQVIA titled, "Patient Access Programs (PAP) in a world of Health Technology Assessment (HTA). The other two panelists were from MOH-Agency for Care Effectiveness (ACE), and AbbVie Pharmaceutical Private Limited.



13 L-R: CAMMY (ABBVIE), FIONA (ACE), NIDHI (CCSS), SOL (IQVIA)



14 Participants from various pharmaceutical companies & IQVIA

At this platform too, Nidhi emphasized the need for decision-makers to engage patients in order to develop a robust patient-centric healthcare system. Patients' needs should be taken into consideration while developing policies, designing research studies, reviewing drug subsidies and cost of innovative therapies.

FINANCIAL ASSISTANCE

CHILDREN'S ASSISTANCE FUND was set-up to reduce the financial burden on families of children with IBD, Our charity bulk purchases Modulen and passes the entire 30% discount to patients. We learnt from Medical Social Workers that some families needed more help. We are grateful to Emtech Wellness International PL for their voluntary support by providing their premises for storage and distribution of Modulen.

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. For the benefit of **families in need of 100% assistance**, Modulen is provided free-of-charge for up to the first six-eight weeks. Subsequent to this initial 6-8 week period of no food, a child is permitted to start taking some food and can continue Modulen as a supplement.

During the current financial year, one child benefitted from the 100% subsidy provided to needy families where nine cartons of Modulen was provided free of charge. Priced at \$1,920 this support is greatly appreciated by the family already struggling to cope with the diagnosis of such a debilitating condition in addition to other stressors. Another six children benefitted from the Children's Assistance Fund.

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. They have been briefed about the high costs associated

with outpatient treatment and management of IBD. In FY 2014-15 we had successfully launched the IBD Monitoring Fund. The initial sum of \$50,000 is part of the planned \$90,000 pilot-project for three years and is intended to benefit the 'sandwich' class based on Per Capita Income.

The logic being that there are existing schemes for those from low-income families while those from the high-income bracket would be able to manage on their own. With no known cure, it is vital to manage these illnesses through regular



15 HENRY LIM PRESENTING CHEQUE TO IBD PATIENTS

monitoring. 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.

During the current financial year 12 families benefitted from this scheme. At \$600 per calendar year, \$7,200 was disbursed to families that met the criteria. CCSS regularly reminds patients on the importance of compliance to doctors' prescribed dosage of medication. Although compliance doesn't provide a guarantee of remission at least the number of episodes of a flare-up of symptoms can be reduced. With more awareness about this assistance scheme we believe more patients will step forward instead of struggling alone.

DONOR APPOINTED REPRESENTATIVE: In June 2017, President Nidhi Swarup served as the Donor Appointed Representative to facilitate an anonymous donation of \$25,000 to the Singapore General Hospital-Department of Gastroenterology and Hepatology.

SINCERE APPRECIATION

We are extremely grateful to the Rotary Club of Raffles City for generously supporting the \$160,000 project to optimize endoscopy in IBD Patients. Our heartfelt appreciation to the Rotary Foundation (TRF), all the partner clubs and Rotary Districts involved to support this invaluable and far reaching project.

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 Takeda, AbbVie and DCH Auriga for their generous support during the year. Without voluntary contributions by our Medical Specialists and subsidized rates provided by the Foundation of Rotary Clubs (S) Ltd for rental of premises for our Patient Support Group meetings, achieving so much in a year would have been quite challenging for us. The guidance and support

provided to IBD Patients by NCSS is much appreciated. We sincerely thank all volunteers, donors and partners for their encouragement and continued support.

For our financial initiatives, we are grateful for the kind and generous contributions received from members of Rotary Clubs and the Crocodile Foundation. On behalf of all beneficiaries and EXCO Members of CCSS, I take this opportunity to thank our volunteers for their untiring contributions and invaluable support.

FUTURE PLANS

- We continue to believe that the general perception of a Support Group will have to be reset for most members of public, newly diagnosed patients as well as their family members. Unlike a stereotypical Patient Support Group, CCSS has a vibrant and buzzing membership where people are willing to exchange ideas and are full of positive energy.
- Support Group Meetings shall be organized periodically for the benefit of IBD patients. We will initiate a separate support group especially designed for children with Crohn's disease or Ulcerative colitis.
- Patients will be encouraged to participate in surveys and research studies. We shall continue to explore collaborative work with experts in IBD to undertake research relevant to patients in Singapore.
- We shall continue to undertake advocacy and make every effort to initiate a National IBD Registry in Singapore.
- Our charity will voice the concerns of our members and explore ways to enhance healthcare provision leading to a seamless support system for patients suffering from Crohn's disease or Ulcerative colitis in Singapore.

Last but not the least, I would like to register my sincere appreciation to the entire team of dedicated volunteers who have been serving tirelessly on the Executive Committee.



Nidhi Swarup (Mrs.)

President

PICTURE GALLERY: FY2017-18

5TH ANNUAL GENERAL MEETING



It seems like time flies, five years have just gone by in a flash! Let's gather to assess how our charity has fared in the Financial Year 2016-17

As for the future, join the discussions to plan a better tomorrow for IBD patients in Singapore

* Dinner will be served after the AGM, all members are cordially invited

AGM Friday, 4th Aug 2017

6.30pm - 8.30pm

Multipurpose Hall, 133 New Bridge Road, Social Service Hub @ Chinatown Point #04-02 Singapore 059413



CROHN'S & COLITIS SOCIETY OF SINGAPORE
237 Arcadia Road #04-06, The Arcadia Block B, Singapore 289844
97564066 | info@ibd.org.sg | www.ibd.org.sg

FOCUS GROUP DISCUSSION

Join us and explore other available options for your child

Make friends with other children with Crohns and Colitis

Share important tips on how other parents cope with their children at home and in school

Date: 07 Oct 2017
Time: 2pm to 4pm
Venue: ChinaTown Point #04-11



DATE
Sat., 10 March 2018

TIME
2.30pm - 4.30PM

VENUE
#04-03 Office Tower
Multi-Purpose Hall
133 New Bridge
Road Chinatown
Point S059413

RSVP
9756 4066



IBD PATIENT SUPPORT GROUP MEETING

- "Navigating IBD and Diet" by Tania Martin-Achard
Join us if you are overwhelmed and/or confused by all the talk about various diets like SCD, Gluten-free, Paleo diet and nutritional needs
- Calligraphy Master Ng Boon Tee will also demonstrate his fine skills as we celebrate CNY 2018 together!
- IBD Patients and family members are most welcome



IBD Patient Support Group Meeting

Saturday, 21 April 2018
2pm - 4pm

Chinatown Point, Training Room 1 (TR1)
Please take **Office Lifts to level 3** & walk up the ramp to #04 (TR1)
133 New Bridge Road, Singapore 059413

- IBD Patients, your family members and friends are invited. We are an informal group that likes to learn from each other. Feel free to join us
- **IBD Monitoring Fund** disbursement
- **Facebook LIVE Event:** "Inflammatory Bowel Disease, Asia Is OK?"
Participate in a chat with an IBD Specialist in Seoul, Korea as well as other overseas patients.

RSVP: WhatsApp or sms **9756 4066**
by 18 April 2018



6th Annual Patient Education & Public Awareness Seminar

Crohn's Disease and Ulcerative Colitis are two most common types of Inflammatory Bowel Diseases (IBD). These are non-infectious, chronic conditions of the digestive tract that require a patient to work closely with the attending Gastroenterologist or IBD Specialist, Nurse, Dietician, Medical Social Worker and Physiotherapist.

Public Awareness about IBD is vital to garner adequate support for a patient who is already trying hard to lead a normal life. Do join us for an afternoon of learning and sharing.

DATE Saturday, 19 May 2018
TIME 12.30pm - 4.30pm
VENUE Mt. Elizabeth Medical Centre
 Level 2, Seminar Room
 3 Mount Elizabeth
 Singapore 228510

REGISTER TODAY

Full Name & NRIC
 WHATSAPP/SMS 9756 4066 (hp)
 CLOSING DATE 13 MAY 2018
LIMITED SEATS

SEMINAR AGENDA

12.30pm - 2pm	Registration and Lunch	
2pm - 2.10pm	Opening Address	 Mrs. Nidhi Swarup Founder & President Crohn's & Colitis Society of Singapore
2.10pm - 2.15pm	Patient Sharing-1	Parent of a Child with Crohn's disease or Ulcerative Colitis
2.15pm - 2.35pm	Inflammatory Bowel Disease (IBD) in Children: Singapore Experience	 Dr Christina Ong Head & Senior Consultant, Gastroenterology Service, KKH
2.35pm - 2.40pm	Patient Sharing-2	A patient who has dealt with Fistula and/or Abscess
2.40pm - 3.00pm	Perianal Crohn's Disease	 Dr Foo Fung Joon Surgeon, Colorectal Surgery, SGH
3.00pm - 3.05pm	Patient Sharing-3	A patient with 50 years of experience dealing with IBD
3.05pm - 3.25pm	Emerging Therapies	 Dr Juanda Leo Hartono Consultant, Division of Gastroenterology & Hepatology, NUH
3.25pm - 3.30pm	Patient Sharing-4	A patient who has tried almost all therapies and is still trying to manage flares and remission
3.30pm - 3.50pm	Biologics and Biosimilars: Same but Different?	 Dr Lin Huiyu Associate Consultant, Gastroenterology & Hepatology, TTSH
3.50pm - 4.10pm	Q & A Session	Panel of Guest Speakers
4.10pm - 4.15pm	Tokens of Appreciation and Vote of Thanks	Mr. Uttam Kripalani, Vice President, Crohn's & Colitis Society of Singapore
4.15PM - 4.30PM	Refreshments	

CCSS is another project initiated by 

VENUE SPONSOR 

SUPPORTED BY  

We couldn't achieve without the invaluable contributions of our expert volunteers, Thank You!



16 ROTARACTOR TAN YONG QUAN:
PHOTOGRAPHER_6TH ANNUAL IBD SEMINAR



17 FACEBOOK LIVE STREAMING: NAWIN SINGH