

# ANNUAL REPORT FY2019-20

1 July 2020

## Summary

In the eighth year of service in Singapore, we continued to create awareness amongst the general public and educate patients 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, advocacy was undertaken on behalf of Crohn's & Colitis Patients. Moreover, we have played a significant role in the recently formed Asia Pacific IBD Alliance.

## 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 ADVISORS



Low Siew Joon



Kaka Singh



Vincent Chen

## OUR EXECUTIVE COMMITTEE



Nidhi  
Swarup



Uttam  
Kripalani



Henry  
Lim



Dr Low  
Cze Hong



Asif  
Baji



Brian  
Tan



Avnish  
Sharma



Shameemullah  
Sulaiman



Sigrid  
Zialcita



Surinder  
Kathpalia

## KEY OFFICE BEARERS

President	Nidhi Swarup
Vice President	Uttam Kripalani
Vice President	Henry Lim
Honorary Secretary	Dr Low Cze Hong
Honorary Treasurer	Asif Baji

## 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

## MEMBERSHIP

During the year 2019-20 membership has increased by 24 of whom seven are children. Current membership stands at 181 of whom 71 are children. There are 40 Life Members and 141 Ordinary Members.

## PATIENT SUPPORT GROUP

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. Owing to the COVID-19 pandemic, we refrained

from organizing Patient Support Group activities. Moreover, the Pediatric IBD Day planned for February 2020 had to be postponed and will be undertaken only if conditions permit. The pediatric Gastroenterology Team, NUH had requested us to organize the event for the benefit of children living with Crohn's disease & Ulcerative colitis and their family members.

Our charity has continued to provide a WhatsApp group to keep IBD Patients and parents of children diagnosed with Crohn's Disease or Ulcerative Colitis connected with each other. Instead of waiting for physical meetings, this application connects patients on a daily basis to encourage peer support and positive thinking. Our WhatsApp group size currently stands at 130 members.

## ANNUAL PUBLIC EDUCATION & AWARENESS SEMINAR

### 1<sup>st</sup> Virtual Asia Pacific IBD Patient Education Seminar 2020

Owing to the COVID-19 pandemic we had to cancel our plans to organize our annual seminar physically. Instead, we celebrated the 8<sup>th</sup> Anniversary of the Crohn's & Colitis Society of Singapore by organizing the 1<sup>st</sup> Virtual Asia Pacific IBD Patient Education Seminar on Monday, 18<sup>th</sup> May 2020. It significantly increased attendance and added an international dimension to allowing for the participation of foreign attendees and international speakers. We had 119 registered attendees from 12 countries. CCSS was able to overcome the challenges presented by the pandemic and came out with flying colours as the event was planned and organized in a record 12 days.

After an opening address by Mrs. Nidhi Swarup each of the guest speakers shared information on various campaigns and support programmes for IBD Patients in their country. It was a pleasure to host guest speakers from Australia, Philippines, Hong Kong, Taiwan, South Korea and Malaysia. Translation services were also arranged in Mandarin and Korean for the benefit of participants from the region.

An IBD App developed by a group of volunteers was also soft-launched after a brief presentation on its features. A group of CCSS Members have volunteered to participate in Beta Testing of this App over the next one-month. In addition to Patient Organizations, three IBD Specialists were invited to speak on COVID-19 related topics as well as on the topic of management of nutritional needs of a patient diagnosed with Crohn's Disease or Ulcerative Colitis. They were Dr Ennaliza Salazar from Singapore General Hospital (SGH), Dr Juanda

Leo Hartono from National University Hospital (NUH) and Dr Veena Logarah from KK Women's & Children's Hospital (KKH). The chat feature in Zoom was used to ask questions and our guest speakers stayed on to oblige. It was a pleasure to note that 84 participants were online at the close of the seminar.

<b>PROFILE OF ATTENDEES</b>		
<b>S. No.</b>	<b>Country</b>	<b>No. of Participants</b>
1	Singapore	56
2	Philippines	38
3	New Zealand	9
4	Hong Kong	3
5	China	3
6	Malaysia	2
7	Thailand	2
8	Japan	1
9	India	1
10	Korea	1
11	UAE	1
12	Australia	1

Three videos were also played for the benefit of participants. The first video was a compilation of congratulatory messages to CCSS from various IBD Patient Organizations in Europe. The second video was a compilation of messages from senior Rotarians, IBD Specialists, Nurses and some IBD patients and their family members. The final video was a fun video on World IBD Day from Takeda. We extend our sincere appreciation to all the contributors for their heartfelt messages and words of encouragement.

We thank Janssen for sponsoring the seminar and DCH Auriga, for sponsorship of goody bags that were delivered to Singapore participants' homes. Owing to the presence of experienced translators and the enthusiastic participation of IBD Patient Organizations from the Asia Pacific Region, this year's seminar was a great success!

## ADVOCACY

During the FY2019-20 we were invited to represent IBD Patients' Voice at various platforms listed below. By accepting opportunities to present the work of Crohn's & Colitis Society of Singapore, we have been able to network with IBD Patient Organizations in the Asia Pacific Region as well as in Europe.

### PARTICIPATION IN OTHER ORGANIZATIONS' EVENTS

S.NO.	DATE	EVENT	ROLE	VENUE
1	Oct 2019	Asia Pacific Alliance for Rare Disease Organizations (APARDO) Summit	Panelist	Taipei, Taiwan
2	Nov 2019	Advisory Board Meeting of IBD Patient Organizations, Boehringer Ingelheim	Panelist	Mainz, Germany
3	Dec 2019	Charity Film Show, Rotary Club of Raffles City	Participant	Singapore
4	Dec 2019	Asia Pacific IBD Alliance Advisory Board Meeting	Participant	Virtual Meeting
5	May 2020	European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA), General Assembly	New Member Panelist	Virtual Meeting
6	Jun 2020	Patient Panel of Go-to-market Virtual Summit, Boehringer Ingelheim	Panelist	Virtual Meeting
7	Jun 2020	In Conversation with Commissioner of Charities, Ministry of Community, Culture & Youth (MCCY)	Participant	Virtual Meeting
8	Jun 2020	Real World Evidence: Meet the Future with Confidence, IQVIA	Participant	Virtual Meeting
9	Jul 2020	IBD Patient Journey, Ferring South East Asia Leadership Training	Panelist	Virtual Meeting

## FINANCIAL ASSISTANCE

**CHILDREN'S ASSISTANCE FUND** In the current financial year, four children benefitted from this assistance fund. 18 cartons of ModulenIBD worth \$6,120 were handed out FOC to the families in need of assistance. This 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 ModulenIBD 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**, ModulenIBD 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 Emtech Wellness International PL for their continued voluntary support with storage and distribution of ModulenIBD.

**IBD MONITORING FUND** During the FY 2019-20 a total of seven members benefitted from this scheme. Based on per capita Income a total of \$4,200 was disbursed to help families of eligible IBD patients. From FY 2014-15 our charity has continued to assist patients from the 'sandwich' class.

While IBD patients from high-income brackets are able to manage on their own, there are government schemes in place for those from low-income families. It is the IBD patient from the middle-income bracket who is left to make ends meet. By providing \$600 per year, our charity hopes to subsidize the cost of blood tests, X-rays, CT Scans, Ultrasound, Colonoscopy or Endoscopy prescribed by the attending specialist.

We regularly remind patients about the importance of compliance to doctors' prescribed dosage of medication. Although compliance does not 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 Khoo 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. Virtual meetings will be organized to complement the WhatsApp group exchanges especially when we cannot hold physical Support Group Meetings. 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, clinical trials and research studies.
- Every effort will be made to initiate a Pan-Asia IBD Registry in partnership with IBD Specialists from the region.

The past eight 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. Moreover, I look forward to leading our charity to reach greater heights in the year ahead.



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Nidhi Swarup (Mrs.)  
President

# PICTURE GALLERY: FY 2019-20



 CROHN'S & COLITIS  
SOCIETY OF SINGAPORE

FOCUS GROUP DISCUSSION PODCASTS

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IBD PATIENT SUPPORT  
GROUP MEETING

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Sat., 21 September 2019

4 PM-6 PM

133 New Bridge Road  
Chinatown Point #04-02/10 S059413

*\*Light refreshments will be provided*

Asia Pacific Alliance for Rare Disease Organizations (APARDO) Summit, Oct 2019 in Taipei Taiwan



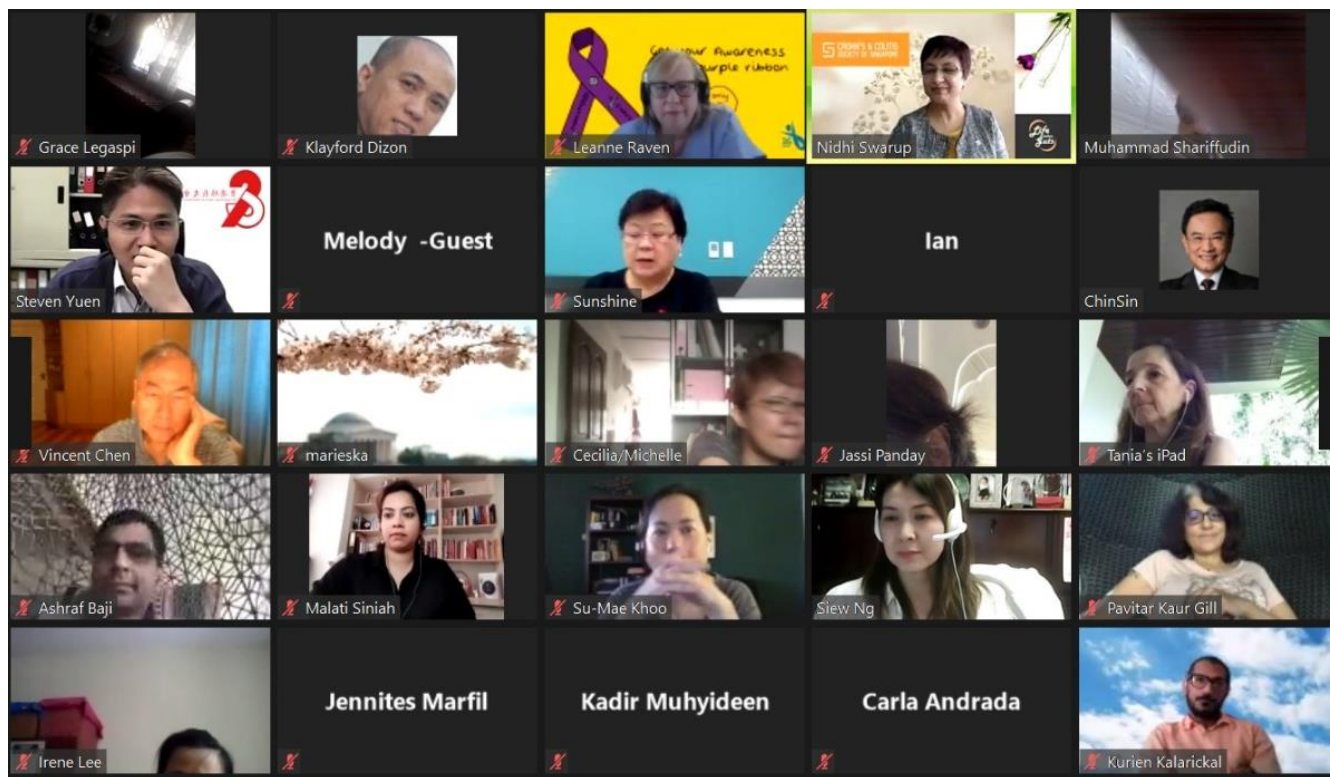


Boehringer-Ingelheim Advisory Board Meeting of IBD Patient Organizations, Nov 2019 in Mainz Germany





## 1<sup>st</sup> Virtual Asia Pacific IBD Patient Education Seminar, May 2020



In conjunction with World IBD Day, the Crohn's and Colitis Society of Singapore is excited to invite you to participate in the inaugural virtual Asia Pacific IBD Patient Education Seminar.

Join us to hear the latest on important IBD topics and engage with fellow patient advocacy organisations and people living with IBD.

**DATE**  
**MONDAY, 18 MAY 2020**

**TIME**  
**12pm – 2pm** | **1pm – 3pm** | **2pm – 4pm**  
Singapore time (GMT +8) | Japan time (GMT +9) | Australia time (GMT +10)

**VENUE**  
**Virtual meeting, [click here](#) to join.**

To confirm your attendance, please register by 5pm Singapore time on Friday 15 May via [this link](#).

### WHAT YOU CAN EXPECT AT THE SEMINAR

- 12:00PM SGT** Welcome address
- 12:10PM SGT** Video screening to mark World IBD Day
- 12:20PM SGT** Patient organisation presentations on patient support activities and assistance services (Australia, Hong Kong, Malaysia, the Philippines)
- 1:00PM SGT** Introduction to a new IBD app resource
- 1:15PM SGT** IBD Specialist presentations:
  1. **Management of paediatric IBD in COVID-19**, Dr Veena Logarajah
  2. **Nutritional needs of IBD patients post-surgery**, Dr Ennaliza Salazar
  3. **COVID-19 and IBD: What patients need to know**, Dr Juana Leo Hartono
- 2:00PM SGT** Closing remarks and end

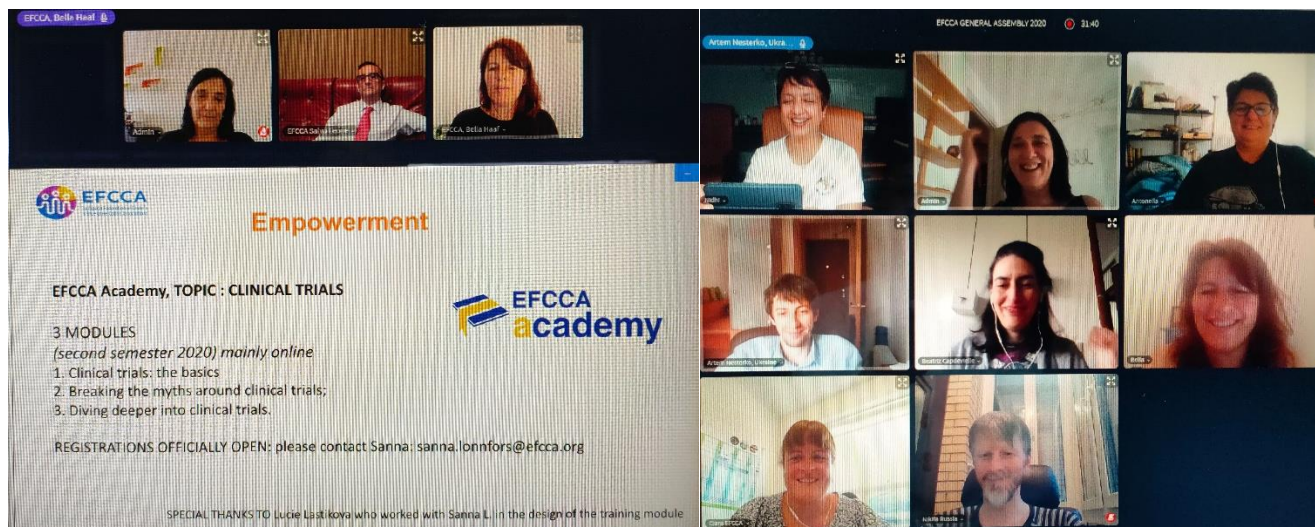
The first 100 CCSS members residing in Singapore to email a screenshot of a redemption card that will be displayed on screen at the end of the meeting will receive goodie packs worth \$100 each. Send the screenshot to [info@ibd.org.sg](mailto:info@ibd.org.sg).

We look forward to hosting you at the 1<sup>st</sup> Virtual Asia Pacific IBD Patient Seminar!

Please contact [info@ibd.org.sg](mailto:info@ibd.org.sg) with any queries.

Sponsored by:

## EFCCA Virtual General Assembly, June 2020



## WHY JOIN EFCCA

### LEARN

- Best Practices in cross country Patient Organizations' collaboration
- IBD Patient Data Sharing
- Patient Advocacy at National Policy Level
- Healthcare Standards

### COLLABORATE

#### Europe Vs Asia Pacific IBD Research

- Epidemiology
- Genetics
- Efficacy of Medication
- Cancer Surveillance
- Burden of Care

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