

## ANNUAL REPORT

## **SUMMARY**

REPORT DATE
30 July 2022

3 December 2021 was a significant day for our charity as the Ministry of Health approved the coveted, Institution of Public Character (IPC) status to our charity. On 7 January 2022, a research paper written with our collaborators and titled, 'Landscape of inflammatory bowel disease in Singapore' was published in the Intestinal Research Journal.

Our charity's first Qualitative Research Study was undertaken, and the report was released on 21 May 2022. A set of Educational Videos by Inflammatory Bowel Disease (IBD) Specialists from four hospitals was also launched during the 10<sup>th</sup> Annual IBD Patient Education & Public Awareness Seminar.

The year saw continued growth in membership, active engagement of members, Children's Assistance Fund and IBD Monitoring Fund being utilized by the patients from low and middle-income families respectively. Our charity continues to reach out to patients by distributing brochures through hospitals and using the website. Social Media channels are included to enhance our efforts to connect with patients diagnosed with Crohn's disease, Ulcerative colitis, and related conditions.



## **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. On 14 January 2014, the Ministry of Health (MOH) granted Charity Status (Registration Number T12SS0090L) to the Crohn's & Colitis Society of Singapore. On 3 December 2021, the coveted status of Institution of Public Character (IPC) was granted by the Ministry of Health (MOH) for a period of one year.

## **KEY OFFICE BEARERS**

President Nidhi Swarup

Vice President Henry Lim

Honorary Secretary Dr Low Cze Hong

Honorary Treasurer Asif Baji

## **OUR MENTORS**







Kaka SINGH



Vincent CHEN



Uttam KRIPALANI



## **OUR EXECUTIVE COMMITTEE**



Nidhi SWARUP President



Henry LIM Vice President



Dr LOW Cze Hong Hon. Secretary



Asif BAJI Hon. Treasurer



Jeffrey CHAN



Brian TAN



Avnish SHARMA



Shameemullah SULAIMAN



Sigrid ZIALCITA



Surinder KATHPALIA

## **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**

Our charity is dependent on gastroenterologists across various hospitals in Singapore to inform patients that the Crohn's & Colitis Society of Singapore (CCSS) is here to provide support. Periodically, we send our official brochures to the hospitals for distribution. Moreover, we keep in touch with the IBD Specialists, Medical Social Workers and IBD Nurses to share our Annual Seminar and Patient Support Group Meeting flyers. New patients can be informed of these meetings. Our invitation is extended to family members of Crohn's disease and Ulcerative colitis patients too.

Family members play a significant role in a patient's journey hence their understanding of the illness severity, symptoms, emotional and financial issues is important. Subsequently, learning how to cope with them comes from our guest speakers as well as members of the patient support group.

During the current financial year, nineteen new members joined CCSS. Current membership stands at 208 of whom 47 are below 18 years of age. There are 44 Life Members and 164 Ordinary Members.





## PATIENT SUPPORT GROUP

Owing to the continued restrictions due to COVID-19 pandemic, we refrained from organizing in-person Patient Support Group activities. The safety of our members takes high priority hence many of our Support Group meetings were held via zoom. Whenever possible in-person meetings were held.

The CCSS members' Signal group continues 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 daily to encourage peer support and positive thinking. Our Signal group size currently stands at 114 members.





## NOVEMBER 2021 PATIENT SUPPORT GROUP MEETING 20th Nov 2021 (Saturday) Time: 2.00pm to 4.00pm Topic: An Overview of Biosimilars Duration: 25-30mins plus Q&A Speaker: Dr Ma. Cristina P. Crisologo, MD, FPOGS, FPSMFM @ 2.15PM inapcrisologo@gmail.com Southeast Asia Cluster Medical Lead – Organon & Co. Clinical Associate Professor – Division of Maternal-Fetal Medicine, University of the Philippines – College of Medicine and Philippine General Hospital Vice Chair for Education — Dept of ObGyn, Asian Hospital and Medical Center Ob Gyn Residency Training and MFM Fellowship Training, — University of the Philippines-College of Medicine and Philippine General Hospital Research Fellowship – Kobe Graduate School of Medicine, Kobe, Japan Join Zoom Meeting https://zoom.us/j/921509451772pwd=K2JSTDVraWs0cm9zVnZDSXp0aTRDQT09 Meeting ID: **921** 5094 5177 Passcode: 485100 RSVP Email info@ibd.org.sg WhatsApp / Signal @ 9756 4066 JANUARY 2022 5 CROHN'S & COLITIS PATIENT SUPPORT GROUP MEETING SATURDAY, 29 JAN 2022 2 PM - 3.30 PM **PROGRAM** . ccss 10th anniversary plans · members' sharing & learning All are welcome! zoom mtg ID: 845 6327 6930 passcode: 543567











## PUBLIC AWARENESS AND PATIENT EDUCATION

#### **BROCHURES**

In our effort to reach out to IBD patients across various hospitals in Singapore, CCSS brochures are sent to them every year.

This year 250 bilingual brochures were sent to the Gastroenterology clinics at Tan Tock Seng Hospital (TTSH), National University Hospital (NUH), and Changi General Hospital (CGH). The other hospitals had sufficient stock from the previous dissemination of CCSS brochures.

#### **SOCIAL MEDIA**

As we continue to reach out to IBD patients and members of public, during this year we have set-up



a social media team to upload our IBD Educational Resources, create and share content via various social media channels such as Instagram, YouTube, Facebook, LinkedIn, and Podcast.



#### IBD EDUCATIONAL VIDEOS – EXPERT SERIES

Five videos were professionally produced by CCSS in collaboration with gastroenterologists from four leading hospitals in Singapore for creating public awareness, and for the benefit of IBD patients. These videos will be made available on CCSS YouTube channel and link provided on the CCSS website. Moreover, this rich information resource will be promoted via social media channels such as Instagram, LinkedIn, and Facebook.

- ♦ Crohn's disease in an adult patient Dr Lin Huiyu, TTSH
- ♦ Ulcerative colitis in an adult patient Dr Malcolm Tan, SGH
- ◆ Crohn's disease in children Dr James Huang, NUH
- Ulcerative colitis in children Dr Veena Logarajah, KKH
- Nutritional requirements & Role of Diet in IBD Patients Dr Ennaliza Salazar, SGH

We would like to acknowledge the educational grant provided by Ferring Pharmaceuticals Pte Ltd for creating these videos.

# 10<sup>th</sup> ANNUAL IBD PATIENT EDUCATION & PUBLIC AWARENESS SEMINAR

In conjunction with World IBD day, CCSS organized the 10<sup>th</sup> Annual IBD Patient Education and Public Awareness Seminar on 21 May 2022. 100 participants were delighted to meet each other in-person after a break of two years when virtual seminars were organized owing to the Covid-19 global pandemic.

Members of public, IBD patients, and their family members were able to learn about the typical symptoms, treatment options, severity of the disease, latest trends, and research findings from our panel of expert speakers. A series of Educational Videos and the First Qualitative Research Report were launched by the GOH, Past District Governor Chew Ghim Bok, Rotary D3310. Tokens of appreciation were also presented to our Medical Advisors for their continued support and guidance over the past 10 years.



### **PROGRAM**

#### 12:00 PM REGISTRATION & LUNCH



1:30PM | OPENING ADDRESS

NIDHI SWARUP
FOUNDER AND PRESIDENT
CROHN'S & COLITIS SOCIETY OF SINGAPORE



1:45PM | CONGRATULATORY MESSAGE SENIOR MINISTER OF STATE, MINISTRY OF HEALTH KOH POH KOON



GUEST OF HONOUR - PAST DISTRICT GOVERNOR CHEW GHIM BOK ROTARY DISTRICT 3310. ROTARY INTERNATIONAL DIRECTOR 2023-25

LAUNCH OF IBD EDUCATIONAL VIDEO SERIES

ANNOUNCEMENT RELEASE OF THE FIRST QUALITATIVE RESEARCH REPORT

RECOGNITION OF MEDICAL ADVISORS
TOKENS OF APPRECIATION FOR 10 YEARS OF SERVICE



2:00 PM | EPIDEMIOLOGY - SINGAPORE IBD REGISTRY

DR WEBBER CHAN

SENIOR CONSULTANT, DEPARTMENT OF GASTROENTEROLOGY AND HEPATOLOGY

DIRECTOR, INFLAMMATORY BOWEL DISEASE SERVICE,

SINGAPORE GENERAL HOSPITAL



2:20 PM | PAEDIATRIC CROHN'S DISEASE

DR VEENA LOGARAJAH

SENIOR CONSULTANT, PAEDIATRIC GASTROENTEROLOGY
KK WOMEN'S AND CHILDREN'S HOSPITAL

#### **5 MINS CONVENIENCE BREAK**



2:45PM | GUT MICROBIOME AND IBD

DR JONATHAN LEE

CONSULTANT, DIVISION OF GASTROENTEROLOGY AND HEPATOLOGY
NATIONAL UNIVERSITY HOSPITAL



3:05 PM | MILD TO MODERATE ULCERATIVE COLITIS
DR RAYMOND LIANG
CONSULTANT, GASTROENTEROLOGY AND HEPATOLOGY
TAN TOCK SENG HOSPITAL

3:25 PM
Q&A - PANEL OF GUEST SPEAKERS
3:50 PM
PRESENTATION OF TOKENS OF APPRECIATION

4:00 PM VOTE OF THANKS | PHOTO TAKING | REFRESHMENTS

EVENT SPONSORS











## RESEARCH AND ADVOCACY

#### INTESTINAL RESEARCH JOURNAL- PAPER PUBLISHED

TITLE - Landscape of inflammatory bowel disease in Singapore

PUBLISHED ONLINE on 7 January 2022

DOI: https://doi.org/10.5217/ir.2021.00089

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Inflammatory bowel disease (IBD), primarily Crohn's disease and ulcerative colitis, had been widely recognized to affect the Western population. However, the notable rise in prevalence of IBD in Asia, including Singapore, had garnered much attention to the causal role of the shift in trend, and more importantly, effective, and safe management of the conditions of these groups of patients in terms of therapy, healthcare economics as well as patient well-being. This review presents a summary of the current landscape of IBD in Singapore and discuss on areas that can be explored to improve and better understand the local condition, as prevalence continues to grow.

#### FIRST QUALITATIVE RESEARCH STUDY - A SIGNIFICANT MILESTONE

While doctors, researchers and other stakeholders would focus primarily on quantitative research, as a charity that is providing emotional, social, and financial support to families dealing with chronic and debilitating conditions like Inflammatory Bowel Diseases, a qualitative research study was considered.

"Everything that can be counted does not necessarily count; everything that counts cannot necessarily be counted." Albert Einstein





Focus Group Discussion on 2 April 2022: Facilitators from Manifeste with patients and parents of children with Crohn's disease,
Ulcerative Colitis or related conditions

In a landscape of a misunderstood disease with substantial burdens, we seek to understand the true impact of Inflammatory Bowel Diseases (IBD) on patients, their caregivers, and the community around them. We used purposeful sampling techniques such as maximum variation sampling for obtaining broad insights and rich information. IBD Patients registered with our charity were invited to participate in a Survey Questionnaire, Focus Group Discussions, and 1-on-1 Patient Journey. The study was conducted between January and April 2022.

As the Crohn's & Colitis Society of Singapore completes 10 years of service to persons diagnosed with Crohn's disease, Ulcerative Colitis, and related conditions, we have achieved a significant milestone by conducting our first Qualitative Research Study. The report was launched during the 10<sup>th</sup> Annual Seminar.

## **EXTERNAL ENGAGEMENTS**

During the FY2021-22, CCSS was invited to represent a Patients' Voice at various platforms listed below. By accepting opportunities to share various lessons learnt and the work of Crohn's & Colitis Society of Singapore, we have been able to network with patient organizations, regulators, and industry partners globally.



#### GLOBAL CLINICAL TRIAL EXPERTS PANEL

Crohn's & Colitis Society of Singapore has been engaged by Boehringer Ingelheim, a German pharmaceutical company to provide a patient's perspective on the Global Clinical Trial Experts Panel. Mrs. Nidhi Swarup, President has been an active participant as a consultant on behalf of CCSS.

#### WHO-UMC-HSA INTER-REGIONAL PHARMACOVIGILANCE TRAINING WORKSHOP

Centre of Regulatory Excellence (CoRE) invited Ms. Nidhi Swarup, CCSS President as a guest speaker to the WHO-UMC\_HSA Inter-Regional Pharmacovigilance Training Workshop held online 20-22 September 2021. She spoke on the topic, "Patient's role in pharmacovigilance communications".







# THE FUTURE OF PATIENT AND PUBLIC INVOLVEMENT IN HEALTH TECHNOLOGY ASSESSMENT (HTA) IN SINGAPORE

The Centre of Regulatory Excellence (CoRE) and Agency for Care Effectiveness (ACE) organized a closed-door discussion on 18 November 2021. Ms. Nidhi Swarup was invited as a panelist to discuss, Subsequently, the ACE Consumer Panel was created which comprises of individuals from local patient organizations who represent a broad range of health conditions and have extensive lived experiences engaging with the Singapore healthcare system.

CCSS Executive Committee member, Mr. Shameemullah Sulaiman has volunteered to serve on the current Panel that has been appointed for a 2-year term from 1 Apr 2022 to 31 Mar 2024.

# EUROPEAN FEDERATION OF CROHN'S & ULCERATIVE COLITIS ASSOCIATIONS (EFCCA)

The Crohn's & Colitis Society of Singapore holds the unique distinction of being the only IBD Patient
Organization from Asia to be a member of EFCCA. As member we were invited to attend the General
Assembly and Strategic Planning Exercise that was held online on 28 May 2022 and in-person 10-12 June 2022 in Barcelona, Spain. Ms. Nidhi Swarup, President represented CCSS at both the meetings.



Figure 1 Isabella Haaf, Deputy Director; Figure 2 L-R: Antonella Cardone (Consultant), Dr Menne Scherpenzeel (Board Member), Nidhi Swarup (CCSS), Salvo Leone (Chairperson), Luisa Avedano (CEO)



## FINANCIAL ASSISTANCE SCHEMES

#### CHILDREN'S ASSISTANCE FUND

This fund was set-up in 2014 to reduce the financial burden on families of children with Crohn's disease or Ulcerative colitis. Generally, children with these diseases are seen by Pediatric Gastroenterologists at KKH and NUH who recommend that children stop taking any food for six to eight weeks. During this period, the child is exclusively on ModulenIBD, a nutritional drink. After the initial period of no food, a child is permitted to start taking some food continue ModulenIBD as a supplement.

Our charity had been purchasing ModulenIBD in bulk and passing the entire 30% discount to patients. We had learnt from Medical Social Workers (MSW) our partners in service, that some families needed more help. So, for the benefit of families in need of 100% assistance, ModulenIBD is provided free-of-charge for up to eight weeks per year. All assessment is undertaken by MSWs.

In the previous financial year, owing to COVID-19 restrictions and associated challenges, CCSS had to develop a new system which is more convenient for members. Purchase orders from members are collated by CCSS and placed with DCH Auriga twice a month. ModulenIBD is delivered to the members' home. During the FY 2021-22, 98 tins of ModulenIBD worth \$2,740 were disbursed for free. Moreover, numerous children's families benefitted from 30% savings negotiated for CCSS Members.

#### IBD MONITORING FUND

While IBD patients from high-income brackets can 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. Regularly going for a consultation with the



doctor and all the tests and scans help monitor the disease activity. Necessary action could be taken to amend medication dosage or type of treatment plan. By providing this assistance CCSS hopes to help members achieve and maintain remission.

Since FY 2014-15 our charity has continued to assist patients from the 'sandwich' class. During the FY 2021-22 a total of nine families benefitted from this scheme that is based on the per capita income of a family. A total of \$5,400 was disbursed to eligible IBD patients.

### **GOVERNANCE**

At CCSS we are committed to upholding and adhering to the principles of good corporate governance as laid out in the Charity Council's *Code of Governance for Charities*. The completed corporate governance checklist for CCSS is accessible at the Charity Council's portal.

The Executive Committee (EXCO) of CCSS takes overall responsibility for its work. The EXCO is responsible for the governance of CCSS and ensures that CCSS is effectively and properly run and meets its overall objectives as set out in its constitution. EXCO meetings are held bi-monthly, where the EXCO members meet to take collective action.

The responsibilities of the EXCO include:

- Setting the direction and strategy of CCSS and monitoring its progress.
- Ensuring the work of CCSS is effective, responsible, and legal.
- Safeguarding finances and resources and ensuring they are used solely to further the CCSS' purposes.
- Monitoring the income and expenditure and ensuring the financial sustainability of CCSS.
- Ensuring the preparation of annual reports and other reporting requirements.

The CCSS constitution does not permit remuneration of the EXCO and no member of the EXCO received any remuneration during the financial year.



## SINCERE APPRECIATION

Gastroenterologists play a significant role in introducing the Crohn's & Colitis Society of Singapore to newly diagnosed IBD patients. We are thankful to our **Panel of Medical Advisors**, Dr Ling Khoon Lin and Dr David Ong, from Mt Elizabeth Hospital, Dr Veena Logarajah from KK Hospital, Dr Juanda Leo Hartono, Dr James Huang, and Prof. Marion Aw from National University Hospital, Prof. Lim Wee Chian and Dr Lin Huiyu from Tan Tock Seng Hospital, Dr Webber Chan, Dr Ennaliza Salazar, and Dr Malcolm Tan from Singapore General Hospital for their invaluable voluntary contributions throughout the year.

A big thank you to all the Nurses, Medical Social Workers, Pharmacists, Dieticians, and allied services teams at various hospitals for supporting IBD Patients. Moreover, we acknowledge and appreciate the support received through Educational Grants from private companies for our patient education and awareness initiatives. We thank our corporate partners Johnson & Johnson, Boehringer Ingelheim, Takeda, Ferring and DCH Auriga for their collaboration with CCSS during this financial year. A special mention for Asian Microbiome Library (AMiLi) for pledging 500 Bio & Me test kits for IBD Patients.

On behalf of our beneficiaries, EXCO Members and Mentors, I take this opportunity to thank all our donors, sponsors, and volunteers for their invaluable support.

## **FUTURE PLANS**

- As forecasted in the Intestinal Research Journal, by 2023 there will be a 1.6-fold increase in the number of persons living with Crohn's disease and Ulcerative colitis. A jump from an estimated 2,000 to 3,200 IBD Patients makes our work more significant. CCSS will work closely with Healthcare Professionals (HCPs) and the soon to be established National IBD Registry to invite more Crohn's disease and Ulcerative colitis patients to join our organization
  - All Crohn's disease and Ulcerative colitis patients will be encouraged to participate in surveys, clinical trials, local and regional research studies.



- ➤ Patient Ambassador Program Pilot at NUH: CCSS patient volunteers will be trained for the implementation of the Patient Ambassador Program. The volunteers will then be equipped with the right skills to visit and support newly diagnosed Crohn's disease and Ulcerative colitis patients as well as CCSS members when they are hospitalized owing to a flare-up of symptoms.
  - ☐ Training videos of information shared by a Doctor, Nurse, Dietician, Pharmacist and MSW will be made available online for the volunteers.
  - ☐ Ambassador Appreciation Program is in place to recognize their time, effort, and commitment
- Qualitative Research Study results will be reviewed by the EXCO, and next steps will be planned to advocate on behalf of the families, and consider action needed to fulfil the unmet needs of patients living with Crohn's disease, Ulcerative colitis, and related conditions.
- Digitalization Project CCSS intends to digitalize its processes in the next financial year with funding support from NCSS.

The past ten 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.

Nidhi Swarup (Mrs.)

President