



# ANNUAL REPORT FY 2020-21

30 July 2021

## Summary

In the ninth year of service in Singapore, our charity provided services online to deal with challenges posed by the COVID-19 pandemic. CCSS Podcast was launched to bring local Crohn's disease and Ulcerative colitis Patient Stories to the public and other Asian patients.

By participating as a speaker, panelist or moderator at various platforms, advocacy was undertaken on behalf of Crohn's & Colitis Patients to enhance healthcare. CCSS is now a member of European Federation of Crohn's & Colitis Associations (EFCCA) and International Alliance of Patient Organizations (IAPO).

## 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



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

## KEY OFFICE BEARERS

President	Nidhi Swarup
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

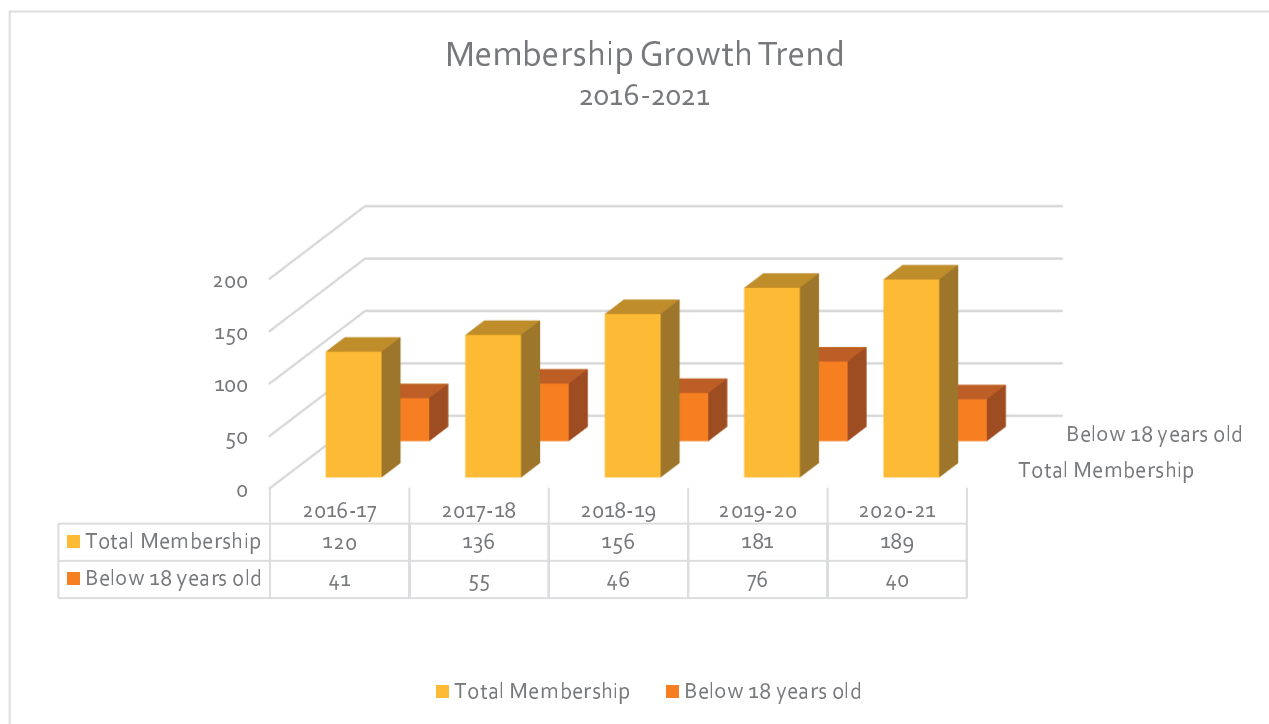
To create a seamless patient support system that improves the quality of life of patients diagnosed with Crohn's Disease, Ulcerative Colitis, and related health conditions with a focus on four key areas:

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

## MEMBERSHIP

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 flyers to the hospitals for distribution. Moreover, we keep in touch with the 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.

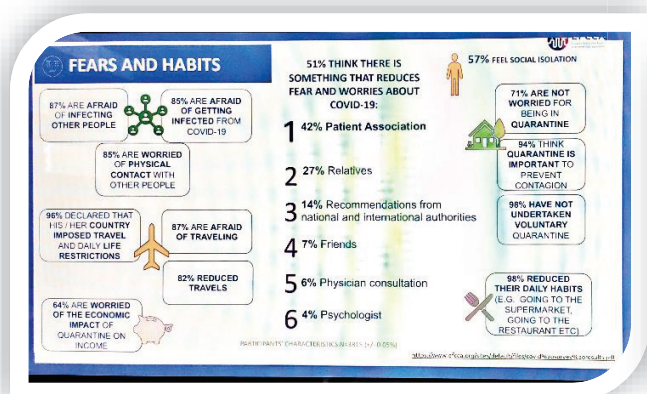
During the current financial year, eight new members joined CCSS. Current membership stands at 189 of whom 40 are below 18 years of age. There are 42 Life Members and 147 Ordinary Members.



## PATIENT SUPPORT GROUP

Owing to the continued restrictions due to COVID-19 pandemic, we refrained from organizing in-person Patient Support Group activities. Moreover, our charity has migrated the chatgroup from WhatsApp to Signal owing to growing concerns over privacy of conversations. The CCSS members' only 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 95 members.

Our inaugural Patient Support Group Meeting via Zoom took place on 29 Aug 2020. Dr Lin Huiyu, Consultant Gastroenterologist from Tan Tock Seng Hospital spoke on *Living with COVID-19*. Given the numerous challenges IBD patients face, the pandemic added another layer of stress. Dr Lin shared information on how lifestyle changes could help members stay healthy and safe. Moreover, members had an opportunity to clarify doubts and fears about their treatment options during such challenging times.



### How can we continue IV infusions?

- Do's
  - Do implement screening procedures for suspected COVID-19 in all patients
  - Do implement measures to minimize crowding
  - Do implement at least 2m distance between chairs
  - Do impose the use of surgical face masks in all patients
  - Do continue biologics at regular intervals and doses
- Don'ts
  - Don't switch infliximab to adalimumab in stable patients unless it is not possible to provide intravenous infusions
  - Don't allow accompanying persons inside the hospital

As a charity that strongly believes in holistic care, after members heard from a Healthcare Professional, we needed an expert to share tips on managing

**Stay Home Stresses In the Time of Covid:  
Managing Its Impact in our lives**

Date: 26th Sept 2020  
Time: 2pm-4pm

Speaker: Dr Nisha Rani, PhD, Clinical Psychologist,  
Centre for Psychotherapy.

Let's come together and learn to live all over again.

At 2pm please join Zoom Meeting

<https://us04web.zoom.us/j/4362106657?pwd=YnBDbXY1eU93MHlQeHM4V0VzRnVaUT09>

Meeting ID: 436 210  
6657Passcode: 9LpdhD

See you then at our upcoming Support Group Meeting!  
Let's all say Hi and get to know our new friends.

**CROHN'S & COLITIS**  
SOCIETY OF SINGAPORE

the mental and emotional health of our members. On 26 Sept 2020, we had invited Dr Nisha Rani, Clinical Psychologist to speak on *Stay Home Stresses in the Times of Covid-19: Managing its impact on our lives*. Members learnt various strategies to manage their mental wellbeing while staying at home.

On 23 January 2021, members of CCSS were fortunate to have two experts talking to us about diet suitable for patients diagnosed with Crohn's disease or Ulcerative colitis.

**IBD Patient Support Group Meeting**  
**Your Diet and Your Gut Microbiome**

**DATE:** Sat, 23 Jan 2021  
**TIME:** 2 pm

**TALK:** Your Diet and Your Gut Microbiome  
**SPEAKER:** Ms Bibi Chia

**Q&A**  
Ms Bibi Chia & Dr Jeremy Lim

**PATIENT SHARING:** 3pm-4pm  
(For CCSS Members ONLY)

**Zoom Meeting ID:**  
971 9154 2547

**Passcode:** 688791

**RSVP Email** info@ibd.org.sg  
**WhatsApp** 9756 4066




**BIBI CHIA**

Bibi Chia is the Principal Dietitian at Raffles Medical Group, with vast experience in the public health, healthcare, and food industries. She is particularly interested in the prevention of nutrition-related non-communicable diseases, and has a strong social media presence building awareness of the importance of nutrition to overall health.

Bibi is currently the Chief Dietitian Consultant at AMILI

**JEREMY LIM**

Prior to AMILI, Jeremy founded global consultancy Oliver Wyman's Asia healthcare consulting practice in 2012. He has held senior executive roles in both the public and private sectors in Asian healthcare including director of research in Singapore's largest healthcare system and Singapore CEO of a Pan-Asian private healthcare group. He continues to serve in the National University of Singapore as co-director of the global health program in the Saw Swee Hock School of Public Health.

Moreover, patients and their family members learnt about the relevance of what they ate to their Gut Microbiome. The presentation was followed by a very interesting Q&A session. All participants had an enriching experience.

On 20 March 2021, CCSS also considered the social challenges faced by a young person living with Crohn's disease or Ulcerative colitis. In fact, living with an incurable disease brings challenges even in a married couple's life. So, if a

patient was seeking a partner for the first time or after a separation, Ms. Violet Lim spoke to members on *Dating & Seeking A Life Partner While Having Lifelong Chronic Illness*.



**Topic: Dating & Seeking A Life Partner While Having Lifelong Chronic illness**



**DATE:** 20 March 2021

**TIME:** 2pm - 3pm  
Guest Speaker Violet Lim, CEO & Co-Founder Of Lunch Actually Group.

**TIME:** 3pm-4pm  
Patients Sharing Session

**RSVP** admin@ibd.org.sg

**Join Zoom Meeting**  
<https://zoom.us/j/94454254731?pwd=c2pzMDlvZFJ2elZlZTFNPRC9wSiYdZ09>

**Meeting ID:** 944 5425 4731

**Passcode:** 109415

\*Friends & Family Members Of Patients Diagnosed With Crohn's Disease And Ulcerative Colitis Are Most Welcome To Join Our Meeting. Together, We Can Make A Difference! ❤️





## PUBLIC AWARENESS AND PATIENT EDUCATION

CCSS PODCAST '*Life takes Guts with Nidhi Swarup*' was launched on 18 May 2021. CCSS is the first charity in Asia to launch a Podcast to bring Patient Stories to the public and for the benefit of other patients living with Crohn's disease or Ulcerative colitis. While there are Podcasts on IBD, they are from Western countries. Nidhi Swarup recorded six episodes via zoom for creating local content. We are grateful to Zaiton & Amir for sharing a parents' perspective, Asik, Enting, Alex and Pavitar for sharing their experience of living with the illness. We are also grateful to Prof. Marion Aw for speaking about pediatric Inflammatory Bowel Diseases (IBD).

### LISTENERS CAN SUBSCRIBE TO ANY OF THE FOLLOWING CHANNELS

Apple Podcasts	Google Podcasts	RSS	Spotify	RadioPublic
Amazon Music	Deezer	iHeart	JioSaavn	
Listen Notes	Player FM	Podcast Addict	Podchaser	



**ZAITON & AMIR**



**ASIK**



**PAVITAR**



ENTING



PROF MARION AW



ALEX

**ANNUAL CROHN'S & COLITIS SEMINAR** In conjunction with World IBD day, we organized the 9<sup>th</sup> Annual Crohn's & Colitis Educational Seminar. Eighty-five participants from various countries joined in via zoom and learnt from our panel of expert speakers.

**YOU ARE INVITED!**

**9<sup>TH</sup> ANNUAL CROHN'S & COLITIS PATIENT EDUCATION SEMINAR**

In conjunction with **World IBD Day**, the Crohn's & Colitis Society of Singapore (CCSS) is excited to invite you to participate in the 9<sup>th</sup> Annual Crohn's & Colitis Patient Education Seminar.

Join us to hear the latest topics related to Inflammatory Bowel Disease (IBD). This is an opportunity to meet and engage with other people living with IBD.

**DATE**  
**Tuesday, 18<sup>th</sup> May 2021**

**TIME**  
**1:00pm - 2:30pm** Singapore time (GMT +8)  
**2:00pm - 3:30pm** Japan time (GMT +9)  
**3:00pm - 4:30pm** Australia time (GMT +10)

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

**WHAT YOU CAN EXPECT AT THE SEMINAR**

1:00PM SGT Opening Address by President of Crohn's & Colitis Society of Singapore

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1:00PM SGT Opening Address by President of Crohn's & Colitis Society of Singapore

1:10PM SGT **Impact of Stress in Children and Youth**  
Dr Veena Loganathan, KK Women's and Children's Hospital, Singapore

1:30PM SGT **National IBD Registry: Research and Clinical Trials**  
Dr Webber Chan, Singapore General Hospital

1:50PM SGT **New IBD Therapies, Covid-19 and Vaccination**  
Dr Juanda Leo Hartono, National University Hospital, Singapore

2:10PM SGT **CCSS Podcast Launch: Life Takes Guts with Nidhi Swarup**

2:15PM SGT **Announcement: Crohn's & Colitis Patient Ambassador Programme**

2:25PM SGT Closing Remarks

2:30PM SGT End

  
**Nidhi Swarup**  
President of Crohn's & Colitis Society of Singapore

  
**Dr Webber Chan**  
Singapore General Hospital

  
**Dr Veena Loganathan**  
KK Women's and Children's Hospital, Singapore

  
**Dr Juanda Leo Hartono**  
National University Hospital, Singapore

Only the first 100 CCSS members residing in Singapore registering to join the meeting will receive a goodie bag (worth \$100) which will be delivered to your home within 1 month after the meeting.

We look forward to hosting you at the 9<sup>th</sup> Annual Crohn's & Colitis Patient Education Seminar!

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

[Click here](#) to register by Friday, 15<sup>th</sup> May 2021

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Supported by 



## ADVOCACY

During the FY2020-21, 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.

**Our Expert Panel**

**Nidhi Swarup**  
Founder and President,  
Crohn's & Colitis  
Society of Singapore  
(Moderator)

**Julie Breneiser**  
Executive Director  
GutIn Syndrome  
Alliance

**Camilla Krogh**  
Lauritzen, Chief Patient  
Officer and Head of  
Patient Engagement, LEO  
Pharma

**Dr Ivana Knezevic**  
MD, Scientist & Team  
Leader, World Health  
Organization

**9th Global Patients Congress**  
16-17 September 2020  
GPC2020.vfairs.com  
Register Now  
FREE  
#GPC2020  
#WorldPatientSafetyDay

**Genetic Disorders and Rare Diseases Patient Co-Creation**  
16 September 2020. 12:40pm BST.

International Alliance of Patients' Organizations  
IAPPO 21 1998 2020

ORGANIZED BY INTERNATIONAL ALLIANCE FOR PATIENT ORGANIZATIONS: SEPT 2020

**Patient Academy for the region, Can EUPATI be replicated in Asia**

**Dr. Ratna Devi**  
Chair, IAPPO (Moderator)

**Lasse Funch Jacobsen**  
Senior Lead, Patient Research and  
Alliances LEO Pharma A/S

**Tamás Bereczky**  
Course Coordinator, EUPATI

**Nidhi Swarup**  
President, Crohn's & Colitis Society of Singapore

**APCP**  
2nd Asia Pacific Patients Congress  
Patients Leadership in Health Systems. Strengthening

International Alliance of Patients' Organizations  
A global voice for patients

ORGANIZED BY INTERNATIONAL ALLIANCE FOR PATIENT ORGANIZATIONS: NOV 2020

## Global Patient Partnership Summit 2021: Guest Speaker and Workshop Moderator on 26 & 27 February 2021



ORGANIZED BY BOEHRINGER INGELHEIM: FEB 2021

**VIRTUAL MEETING**

**DIA-CoRE Singapore Annual Meeting 2021**  
**Catalysts for Changes – Preparing for the Future of Healthcare**  
 Organised by DIA and CoRE  
**7 - 8 JULY 2021**

**11.00-12.00noon**    **Panel Discussion : Optimising contributions to healthcare systems**

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**Moderator**  
**James Leong**  
 Head - Health Products & Regulatory Science  
 Centre of Regulatory Excellence (CoRE)  
 Duke-NUS Medical School

**Panelists**

<b>Cheng Leng Chan</b> Group Director - Health Products Regulation Group Health Sciences Authority Singapore	<b>Steven Tucker</b> Founder Tucker Medical Singapore	<b>Hishamuddin Badaruddin</b> Adj Asst Professor Duke-NUS Graduate Medical School	<b>Nidhi Swarup</b> Founder & President Crohn's & Colitis Society of Singapore
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ORGANIZED BY CENTRE OF REGULATORY EXCELLENCE - DIA: JULY 2021

## FINANCIAL ASSISTANCE

**CHILDREN'S ASSISTANCE 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 current 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 2020-21 one child benefitted from the 100% assistance fund while numerous children's families benefitted from substantial 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.

During the FY 2020-21 a total of three families benefitted from this scheme that is based on the per capita income of a family. A total of \$1,800 was disbursed to eligible IBD patients. Since FY 2014-15 our charity has continued to assist patients from the 'sandwich' class.

## 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 from Mt Elizabeth Hospital, Dr Veena Logarajah from KK Hospital, Dr David Ong, Dr Juanda Leo Hartono, and Prof. Marion Aw from National University Hospital for their invaluable voluntary contributions throughout the year. We also register our gratitude to Gastroenterologists Prof. Lim Wee Chian from Tan Tock Seng Hospital, Dr Webber Chan from Singapore General Hospital and Dr Malcolm Tan from Changi General Hospital who have kindly continued to serve on our Panel of Medical Advisors.

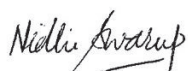
Owing to Educational Grants from pharmaceutical companies many of our patient education and awareness initiatives have been possible. We thank our corporate partners Boehringer Ingelheim, Pfizer, Takeda, Ferring and DCH Auriga for their collaboration with CCSS during this financial year. Without voluntary contributions from our Medical Specialists, achieving so much in a year would have been quite challenging for us. 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

- **Virtual Patient Support Group Meetings** will continue periodically for the benefit of members until it is declared safe by the authorities to meet in-person
- **IBD Educational Videos** in collaboration with gastroenterologists from various hospitals for the benefit of public and patients in Singapore

- CCSS will work closely with Healthcare Professionals (HCPs) and the **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 by us 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

The past nine 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