

## *Vision, Mission and Values*

- ▶ **Our Vision:** A world where steatotic liver disease (previously known as fatty liver disease) and other common liver diseases are rare and treatment and care for those with the disease is timely
- ▶ **Our Mission:** Support experts in different field (hepatology, gastroenterology, diabetology, primary care and nutrition) to advance knowledge and the uptake of solutions to understand, prevent, manage and treat SLD and other common liver diseases
- ▶ **Our Values:**
  - ▶ **Leadership** – *we're helping to set the global agenda*
  - ▶ **Collaboration** – *we're building a global community by collaborating with all stakeholders*
  - ▶ **Person-Centred** – *we're addressing questions that matter to patients and affected communities*
  - ▶ **Impact focused** – *we're focused on biggest challenges and opportunities*

### ***Our ambition for the GNC/GLC***

To be recognised within the liver health and global health communities as the preeminent global think-tank for steatotic liver disease (SLD) and other important LDs



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## The Global NASH and Liver Councils

### *Organizational goals*



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Facilitate **collaborative research** on disease burden, prevention, management and care



Grow and nurture the **community of thought leaders** in the field of SLD and other common liver diseases



**Provide thought leadership** within the field

**The Global NASH/MASH Council**  
*Facilitate collaborative research on the prevention,  
 management & care of SLD*



### GNC value proposition

**For SLD researchers:** We help GNC researchers around the world to collaborate on SLD research by providing a platform for engagement and making available unique data and resources (both human and financial).

**For research funders:** The GNC helps research funders (public/private) to answer key questions by providing access to a network of leading experts and by leveraging data that only GNC members can access

### GNC objectives

- Grow and strengthen the Global NASH Registry™ and the Global Liver Registry™
- Undertake original research to advance knowledge on both supply and demand side of SLD prevention, management and care
- Pursue multisectoral and interdisciplinary collaboration

### GNC competitive advantages

- Ownership of the Global NASH Registry™ and Global Liver Registry™
- Leaders in developing and validating quality of life instruments and performing PRO data analysis (e.g CLDQ-NASH)
- Established membership of world leading SLD researchers spanning >40 countries
- Unique expertise in specific areas, including epidemiologic research, lifestyle intervention research, policy research and outcomes research (clinical, patient, economic)

**Where the GNC won't focus:** The GNC will not enroll patients in clinical trials



## GNC value proposition

**For the liver health community:** The GNC helps to grow the SLD community of practice (CoP) by providing a platform that enables members to connect, exchange ideas and initiate collaborations, through which the GNC broaden and deepens the SLD CoP within and beyond the field of hepatology

**For GNC members:** The GNC helps members to grow their own network by providing a platform to engage and interact with peers and experts that are otherwise outside of their immediate CoP creating professional opportunities that are beneficial to individual members and to the wider community

## GNC objectives

- Deepen the CoP (i.e. expansion within the hepatology field) by grow the GNC membership with a focus on countries and regions where the membership is small
- Broaden the CoP (i.e. expansion outside of the field of hepatology) by strategically targeting the endocrine field and primary care/family doctors in the next 5-year period
- Promote more organisational collaborations (alongside individual membership) by establish GNC collaborating organisations and endorsing organisations

## GNC competitive advantages

- A readymade platform which has 104 members from more than 40 countries, including the most influential thinkers in the field
- A lightweight governance structure that allows for greater agility than other membership organisations (e.g. scientific/clinical associations)
- Established links to outside of hepatology which can be grown and strengthened in the next 5 years

**Where the GNC won't focus:** The GNC will not duplicate the role of national/regional liver associations.

## The Global NASH/MASH Council

*Provide thought leadership within the field of SLD*



### GNC value proposition

**For the liver health community:** The GNC gathers the leading global thinkers and visionaries on SLD to debate the major issues and opportunities within the field and to help shape and deliver transformative agendas across research, policy and practice.

### GNC objectives

- Build the GNC brand to be globally recognised within and outside of the liver community as the leading think-tank on SLD
- Advance the key issues and debates within the field and help to build consensus on the way forward in currently neglected or contentious issues
- Support efforts to catalyse and accelerate positive change by documenting advancing in the field

### GNC competitive advantages

- The leading voices on SLD are already engaged within the GNC, we can leverage this to bring the most forward-thinking ideas and perspectives to the field.
- Greater flexibility in both strategic and operational approaches than other membership organisations or academic institutions in the field meaning the GNC can pivot and flex as the needs of the field evolve

## Strengthening leadership and coordination mechanisms

### Broadening the GNC/GLC leadership group

- Creation of a leadership committee to support the shaping and delivering our strategy

### Strengthening GNC/GLC coordination mechanisms

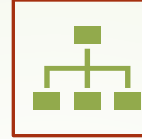
- Creation of eight committees to lead GNC/GLC work on key themes
- Two co-chairs per committee to lead the activities along with 10-12 members
- Co-chair sit on the leadership committee to enable coordination across all work areas

### Growing organisational collaborations

- Engagement organisations across the liver health and broader global health community to build institutional collaborations that leverage our shared capabilities and goals
- Formalise engagements with other organisations as either *collaborators* or *endorsers*

# The Global NASH and Liver Councils

*Strengthening leadership and coordination mechanisms*



Leadership Steering committee

CORLD-Business Director

GNC-Lifestyle Committee

GNC-Clinical & Patient Outcomes Committee

GNC-Policy, Public Health & Disparity Committee

GNC-NIT Committee

Hepatology and Non-Hepatology Interface Committee

Cholestatic Liver Disease Committee

Viral hepatitis

Patient Advocacy Committee

GNC/GLC Membership



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# The Global NASH and Liver Councils

## *Committees leadership and members*



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**Leadership Steering Committee:** Zobair Younossi (GNC Chair), Jeff Lazarus, Shira Zelber-Sagi, Lynn Gerber, Saleh Alqahtani, Alina Allen, Ken Cusi, Paula Macedo, Laurent Castera, Leyla DeAvila, Henry L, Pegah Golabi, Fatema Nader (PD) and Henry Mark (PD)

**Lifestyle Committee Co-Chairs:** Shira Zelber-Sagi and Lynn Gerber (PD: Leyla DeAvila)

Members: Zobair Younossi, Jillian Price, Dana Ivancovsky, Saleh Alqahtani, Ali Weinstein, Paola Andrenacci, Manisha Verma, Carina Kugelmas, Suzi Gerber, Mohamed El-Kassas, CJ Liu, Fatema Nader, Mani Srishord, Andrei Racila

**Clinical & Patient Outcomes Committee Co-Chair:**s Zobair Younossi and Saleh Alqahtani (PD: Henry L)

Members: Patrizia Burra, Robert Wong, Janus Ong, Marlen Fernandez, Ashwani Singal, Jorn Schattenberg, Sven Franque, Stepanova M, Patrizia Carrieri, Jeff Lazarus, Manisha Verma

**Policy, Public Health & Health Disparity Committee Co-Chairs:** Zobair Younossi and Jeffrey Lazarus (PD: Fatema Nader)

Members: Nadage Gunn, Claudia Pinto Marques Souza Oliveira, Vincent Wong, Saleh Alqahtani, Alexander Krag, Shira Zelber, Sagi, Yusuf Yilmaz and Henry Mark

**Hepatology and Non-Hepatology Interface Committee Co-Chairs:** Ken Cusi and Paula Macedo (PD: Pegah Golabi)

Members: Scott Isaacs, Brian Lam, Giulio Marchesini, Amila Gestadelli, Paul Brennan, Zobair Younossi (Ad-Hoc)

**NIT Committee Co-Chairs:** Alina Allen and Laurent Castera (PD: Pegah Golabi)

Members: Mazen Nouredine, Marcelo Kugelmas, Naim Alkhoury, Vincent Wong, Jorn Schattenberg, Yusuf Yilmaz and Zobair Younossi (Ad-Hoc)

**Viral Hepatitis Committee Co-Chairs:** Maria Buti MD and George Papatheodoridis (PD: Henry L)

Members: Wah Kheong Chan, Mohammad El Kassas, Stuart Gordon, Vasily Isakov, Ira Jacobson, Yusuf Yilmaz, Ming Lung Yu

**Cholestatic Liver Disease Committee Co-Chairs:** Co-Chair: Andeas Kremer and Z Younossi (PD: Pegah Golabi)

Mark Swain, Dave Jones, Michael Trauner, Nikolaos Pylsopoulos and Gideon Hirschfield

**Alcoholic Liver Disease Committee Co-Chairs:** Co-Chair: Ashwani Singal and TBD

Members: Juan Pablo Arab, Javier Crespo, Aleksander Krag, Mario Passeo, Robert Wong, Yusuf Yilmaz, Zobair Younossi (Ad Hoc)

**Patient Advisory Committee:** Achim Kautz, Nikos Dedes

Members: TBD



### Leadership committee

- Set the **GNC strategy** within put from the members
- Overall **operational oversight** (supported by CORLD Business Director)
- Oversee and **approve programmatic** activities and ensure alignment with the organisational goals
- Update the GNC membership regarding the council's work

### Role of the committee co-chairs

- Provide **leadership** within the **committee** and chair meetings
- Propose activities for the committee members to consider
- Responsible for at least **2 projects** within the area of committee's interest
- Be a liaison between the thematic committee and the leadership committee

### Role of the Project Directors

- Support the co-chairs in running the committee including setting calls and agendas, drafting workplans, research, funding proposals and overseeing activities
- Stays in regular communication with Global Liver Registry sites participating in research and reports progress updates.

### Thematic committees

- Lead the GNCs activities within a given thematic
- Establish programmatic priorities, develop proposals and where appropriate support fundraising efforts

### Role of the committee members

- **Engage** actively within the committee and attend quarterly meetings
- Active engagement of GNC projects
- Encourage **enrolment in the Global Registries**
- Provide insights and ideas as to the focus of the committee's activities
- **Contribute to the delivery of agreed activities (e.g. research, publications)**



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# The Global NASH and Liver Councils

Being an active GNC member – ways to engage



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## Support The Global Registries

- Actively enrol and encourage other country side to become engaged
- Adhere to data integrity process

## Support a GNC/GLC Committee

- Each committees has 10—12 GNC members
- Members are committed to actively contributing to the committee's work, including attending quarterly meetings and supporting programmatic activities

## Contribute to GNC/GLC publications

- GNC members regularly publishes original research, reviews and thought leadership pieces
- Where relevant and appropriate steering committee members can include the GNC as an affiliation in publications
- The GNC follows ICMJE guidelines on authorship

## Participate in GNC/GLC meetings

- The GNC brings members together regularly including at AASLD and EASL conferences, members are encouraged to attend meetings to share ideas and updates and to network with other GNC members

## Share ideas on how the GNC/GLC can achieve its ambition

- Members are encouraged to reach out to the leadership with ideas on how the council can best serve its members and achieve its ambition

## *Purpose of Global Registries*

- Real world data regarding the clinical and PRO outcomes of important liver diseases are not available.
- The Global NASH and Liver Registries were established by COR-LD as a global collaboration effort to obtain clinical and PRO data for important liver diseases
- Historical: HBV, HCV, HDV and NAFLD/MASLD
- In 2023, we added ALD and PBC as new enrollment criteria
- The Global Registry requires e-data collection after informed consent (IRB approved)
- The Global Liver/NASH Registries currently have 28 active sites
- These sites represent all the continents
- The intention is to compare liver diseases including MASLD, Met-ALD and others from different regions of the world using the Global Registry data

# The Global Registries

## *Types of Liver Disease and Data Collection*

### **Population:**

- IRB approval for US sites through WIRB
- Up to 100,000 subjects will be enrolled into the registries with 10 years of follow up:
- **Types of liver diseases:**
  1. NAFLD/MASLD: NAFLD/MASLD or NASH/MASH subjects with an established diagnosis by historical liver biopsy or accepted imaging technique (ultrasound, CT, MRI, TE)
  2. Chronic HCV with viremia (regardless of treatment)
  3. Chronic HBV (who are carriers of HBsAg) (regardless of treatment)
  4. Chronic HDV (regardless of treatment)
  5. PBC: 1) ALP > 2 x ULN or GGT > 5 x ULN and 2) AMA > 1:40. Other histologic evidence of PBC according to the guidelines are also accepted.
  6. ALD: 1) Meet criteria for AUD 2) Evidence of any liver disease (elevated aminotransferases outside the laboratory range, fatty liver SH or cirrhosis) by clinical, laboratory, radiologic or biopsy proven can be considered to have ALD.
- **Data Collection:**
  - Clinical and Laboratory data
  - Clinical Outcomes
  - Patient Reported Outcomes:
    - **HCV:** complete 4 questionnaires: CLDQ-HCV, FACIT-F, WPAI, a Short Form Health Disparity questionnaire
    - **HBV and HDV:** complete 4 questionnaires: CLDQ-HBV, FACIT-F, WPAI, and a Short Form Health Disparity questionnaire
    - **NAFLD/MASLD:** complete 6 questionnaires: CLDQ-NAFLD, FACIT-F, WPAI, Activity Questionnaire, Nutrition Questionnaire and Short Form of Health Insecurity Questionnaire
    - **PBC:** complete 6 questionnaires: CLDQ-PBC, FACIT-F, WPAI, Short Form of Health Disparity questionnaire, PBC-40 and 5D-itch
    - **ALD:** complete 5 questionnaires (CLDQ or CLDQ-ALD (being developed), FACIT-F, WPAI, Short Form of Health Disparity questionnaire and AUDIT-C questionnaire
  - Liver stiffness, pathology and radiology (if available)
  - Baseline and annual follow ups



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## The Global NASH and Liver Councils *Scientific Support Team Members*



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- **Lead Statistician and Senior Investigator, CORLD and GNC:**

- Maria Stepanova PhD
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- **Lead Statistician and Senior Investigator, GNC:**

- James Paik PhD
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- **Business Director, CORLD**

- **Project Director, GNC Leadership Steering Committee and Policy, Public Health & Health Disparity Committee**

- Fatema H. Nader, MSBM, CCRC, CCRA
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- **Medical Writer and Senior Investigator**
- **Project Director, GNC Clinical & Patient Outcomes Committee and GLC Viral Hepatitis Committee**

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- **Project Director: GNC Lifestyle Committee**

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- **Project Director, GNC Diabetology Committee and NIT Committee**

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