

# 1<sup>ST</sup> INTERNATIONAL AL AMYLOIDOSIS MEETING

FOR PATIENTS AND DOCTORS



5-6 July, 2024  
BRUSSELS



[ALamyloidosismeeting.com](http://ALamyloidosismeeting.com)

## PRELIMINARY PROGRAM

ORGANIZED BY:



**AMYLOIDOSIS  
ALLIANCE**  
THE VOICE OF PATIENTS

WITH THE COLLABORATION OF:



INSTITUT  
JULES BORDET



Centre national de référence

**Amylose AL**

& autres maladies par dépôts d'immunoglobulines monoclonales



**ISA**

INTERNATIONAL SOCIETY  
OF AMYLOIDOSIS

**1<sup>ST</sup> INTERNATIONAL  
AL AMYLOIDOSIS  
MEETING**  
FOR PATIENTS AND DOCTORS

**5-6 July, 2024  
BRUSSELS**



# **JOIN US IN BRUSSELS!**

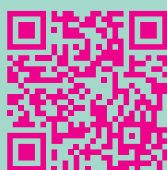
The Amyloidosis Alliance is pleased to welcome you to the first International AL Amyloidosis Meeting, which will be held in Brussels on July 5-6, 2024.

This two-day program will be an extraordinary opportunity to gain insights into all aspects of AL amyloidosis, with a special focus on managing complications linked to organ involvement. It will also provide occasions for patients and medical doctors to learn from each other's experiences.

On the first day, there will be sessions dedicated to patients, and separate sessions for doctors. The second day will feature joint sessions for both groups.

We hope to meet you in Brussels and wish you an inspiring congress!

**Agnès FARRUGIA, Frank BRIDOUX and Nathalie MEULEMAN**  
*On behalf of the organizing committee*



**REGISTRATION AND INFORMATION:**  
[ALamyloidosismeeting.com](https://ALamyloidosismeeting.com)



## ORGANIZING COMMITTEE

- **Prof. Nathalie MEULEMAN**  
Institut Jules Bordet (HUB),  
Brussels, Belgium
- **Prof. Frank BRIDOUX**  
Centre de référence  
amylose AL, Poitiers, France
- **Jean-Christophe FIDALGO**  
President of the Amyloidosis  
Alliance, France
- **Prof. Stefan SCHÖNLAND**  
Hämatologie, Onkologie und  
Rheumatologie Zentrum für  
Innere Medizin, Heidelberg,  
Germany
- **Agnès FARRUGIA**  
Director of the Amyloidosis  
Alliance, France
- **Prof. Thibaud DAMY**  
Centre de Référence  
des Amyloses Cardiaques,  
Paris, France
- **Prof. Arnaud JACCARD**  
Centre de Référence Amylose  
AL, Limoges, France
- **Prof. Efstathios KASTRITIS**  
National and Kapodistrian  
University of Athens, Greece
- **Prof. Olivier LAIREZ**  
Institut des Maladies  
Métaboliques et  
Cardiovasculaires,  
Toulouse, France
- **Barbara MAZZOLINI**  
Association Française  
contre l'Amylose, France
- **Prof. Monique MINNEMA**  
Academic Medical Center,  
Utrecht, The Netherlands
- **Dr Ben WOLTERING**  
Amyloidosis Alliance,  
The Netherlands

## SCIENTIFIC COMMITTEE

- **Prof. Antoine BONDUE**  
Hôpital Universitaire  
de Bruxelles, Belgium
- **Prof. Frank BRIDOUX**  
Centre de Référence  
Amylose AL, Poitiers, France
- **Prof. Thibaud DAMY**  
Centre de Référence  
des Amyloses Cardiaques,  
Paris, France
- **Agnès FARRUGIA**  
Director of the Amyloidosis  
Alliance, France
- **Dr Simon GIBBS**  
Peter MacCallum Cancer  
Centre, Melbourne, Australia
- **Prof. Ute HEGENBART**  
Amyloidose Zentrum,  
Universitätsklinikum  
Heidelberg, Germany
- **Prof. Arnaud JACCARD**  
Centre de Référence  
Amylose AL, Limoges, France
- **Prof. Efstathios KASTRITIS**  
National and Kapodistrian  
University of Athens, Greece
- **Prof. Olivier LAIREZ**  
Institut des Maladies  
Métaboliques et  
Cardiovasculaires,  
Toulouse, France
- **Dr Nelson LEUNG**  
Mayo Clinic, Rochester, USA
- **Barbara MAZZOLINI**  
Association Française contre  
l'Amylose, France
- **Prof. Nathalie MEULEMAN**  
Institut Jules Bordet (HUB),  
Brussels, Belgium
- **Prof. Monique MINNEMA**  
Academic Medical Center,  
Utrecht, The Netherlands
- **Prof. Giovanni PALLADINI**  
Amyloidosis Research and  
Treatment Center, Pavia, Italy
- **Dr Virginie PASCAL**  
CHU de Limoges, France
- **Prof. Stefan SCHÖNLAND**  
Hämatologie, Onkologie  
und Rheumatologie Zentrum  
für Innere Medizin,  
Heidelberg, Germany
- **Prof. Christophe SIRAC**  
CHU de Limoges, France
- **Prof. Ben SPRANGERS**  
Ziekenhuis Oost-Limburg,  
Leuven, Belgium
- **Prof. Ashutosh  
WECHALEKAR**  
Royal Free London Foundation  
Trust, Great Britain
- **Dr Ben WOLTERING**  
Amyloidosis Alliance,  
The Netherlands



# DOCTORS CHANNEL

## FRIDAY, JULY 5

**08:00 - 08:30 am**

**REGISTRATION** - Welcome coffee | Visit exhibit

**08:30 - 09:00 am**

**INTRODUCTION**

**09:00 - 10:00 am**

**SESSION 1**

**Latest medical advances in pathophysiology**

*Chairmen:* **Stefano Ricagno (Milano, Italy), Arnaud Jaccard (Limoges, France)**

- 09:00 Recent insights into the structure and formation of AL amyloid fibrils  
Marcus Fändrich (Ulm, Germany)
- 09:15 Recent insights from in vivo models into AL amyloid fibrils accumulation and toxicity for organs  
Christophe SIRAC (Limoges, France)
- 09:30 How do fibrils disappear?  
Julian Gillmore (London, Great Britain)
- 09:45 Discussion

**10:00 - 11:00 am**

**SESSION 2**

**Supportive care of treatments of involved organs - Part 1**

*Chairmen:* **Thibaud Damy (Créteil, France), Lluís Quintana (Barcelona, Spain), Helen Lachmann (London, GB)**

- 10:00 **Kidney**  
Lluís Quintana (Barcelona, Spain)
- 10:20 **Kidney transplantation**  
Nelson Leung (Rochester, USA)
- 10:40 **Cardiac**  
Michelle Michels (Rotterdam, The Netherlands)
- 11:00 Round table

**11:20 - 11:50 am**

Coffee break | Visit exhibit

**11:50 am - 01:00 pm**

**SESSION 2**

**Supportive care of treatments of involved organs - Part 2**

- 11:50 **Peripheral nervous system**
- 12:10 **Others: GI, nutrition, hypotension, fatigue, muscle loss, sexual dysfunction**  
Laura Obici (Pavia, Italy)
- 12:30 Round table



**FRIDAY, JULY 5**

**DOCTORS  
CHANNEL**

.../...

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01:00 - 02:30 pm      Lunch time

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**02:30 - 03:15 pm      INDUSTRY SYMPOSIUM**

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**03:15 - 04:15 pm      SESSION 3**

**How to assess the response to treatments?**

*Chairmen:*      *Monique Minnema (Utrecht, The Netherlands),  
Nathalie Meuleman (Brussels, Belgium)*

- |       |                                                                                                                        |
|-------|------------------------------------------------------------------------------------------------------------------------|
| 03:15 | <b>Biology of the clone</b><br>Stefan Schönland (Heidelberg, Germany)                                                  |
| 03:35 | <b>Utility of minimal residual disease assessment in AL Amylodoisis</b><br>Ashutosh Wechalekar (London, Great Britain) |
| 03:55 | <b>Light chain instability in AL amyloidosis</b><br>Jeffery Kelly (La Jolia, USA)                                      |
| 04.15 | Discussion                                                                                                             |
- 

04:30 - 05:00 pm      Coffee break | Visit exhibit

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**05:00 - 06:30 pm      SESSION 4**

**Complex clinical cases**

*Chairmen:*      *Frank Bridoux (Poitiers, France), Stefan Schönland (Heidelberg, Germany)*

- Diagnostic
  - Difficult treatment
  - Long term remission
- 

06:30 pm      **END OF THE FIRST DAY**

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08:15 pm      **DINNER**

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# PATIENTS ASSOCIATIONS CHANNEL

## FRIDAY, JULY 5

**08:00 - 08:30 am**

**REGISTRATION** - Welcome coffee | Visit exhibit

**08:30 - 09:00 am**

### INTRODUCTION

**Amyloidosis Alliance introduction and actions**  
Jean-Christophe Fidalgo

**09:00 - 10:45 am**

### SESSION 1

**Diagnosis improvement and 2024 critical point**

- 09:00 Diagnosis: patients journey testimonies
- 09:30 How to reduce time to diagnosis in 2024?  
Nathalie Meuleman (Brussels, Belgium)
- 09:50 How to improve the accurate diagnosis in 2024?  
Christoph Röcken (Kiel, Germany)
- 10:10 Multidisciplinary approach for improving the diagnosis?  
Laura Obici (Pavia, Italy)
- 10:30 Discussion

**10:45 - 11:15 am**

Coffee break | Visit exhibit

**11:15 am - 01:00 pm**

### SESSION 2

**Medical care and symptoms treatment**

**Chairmen:** *Thibaud Damy (Créteil, France), Lluís Quintana (Barcelona, Spain),  
Helen Lachmann (London, Great Britain)*

- 11:15 **Kidney**  
Lluís Quintana (Barcelona, Spain)
- 11:30 **Dialysis**  
Anne-Lorraine Clause (Brussels, Belgium)
- 11:45 **Cardiac**  
Christian Knackstedt (Maastricht, The Netherlands)
- 12:00 **Peripheral nervous system**  
Gauthier Remiche (Brussels, Belgium)
- 12:15 **Others (malnutrition, macroglossia, dysgeusia)**  
Laura Obici (Pavia, Italy)
- 12:30 Discussion



# PATIENTS ASSOCIATIONS CHANNEL

## FRIDAY, JULY 5

.../...

01:00 - 02:30 pm Lunch time

### 02:30 - 03:00 pm **INDUSTRY SYMPOSIUM**

03:00 - 04:30 pm

#### **SESSION 3**

**Importance of self-care: physical, mental and emotional wellbeing**

*Chairmen:*

*Barbara Mazzolini (Association Française contre l'Amylose),  
Ben Woltering (Amyloidosis Alliance, The Netherlands)*

- 03:00 Complementary treatments: the French experience  
Julie Pompougnac (Créteil, France)
- 03:15 Kinesiology / Music therapy  
Audrey Norris, Barbara Mazzolini (Association Française contre l'Amylose)
- 03:30 Dietetic and environment during and after the treatment
- 03:45 Physical training for amyloidosis patients during the treatment  
Isabel Kristen (Heidelberg, Germany)
- 04:00 Role of patient's organisation and care givers  
David Gregory (The Ukpatha, Great Britain)
- 04:15 Discussion

04:30 - 05:00 pm Coffee break | Visit exhibit

05:00 - 06:00 pm

#### **SESSION 4**

**Return to normal life after treatment**

*Chairmen:*

*Agnès Farrugia (Association Française contre l'Amylose),  
Guy Lippens (Amybel, Belgium)*

- 05:00 Vaccines and prevention  
Ornella Rizzo (Brussels, Belgium)
- 05:15 Travels and health insurance  
Danièle Rousseau (Paris, France)
- 05:30 Muscular rehabilitation and sport  
Agnès Morier (Le Kremlin-Bicêtre, France)
- 05:45 Discussion



# PATIENTS ASSOCIATIONS CHANNEL

## FRIDAY, JULY 5

.../...

06:00 - 06:45 pm

### SESSION 5

#### Return to work

**Chairmen:** *Barbara Mazzolini (Association Française contre l'Amylose),  
Julie Pompougnac (Créteil, France),  
Ben Woltering (Amyloidosis Alliance, The Netherlands)*

06:00 Testimonies: return to work share experience

06:15 Round table  
Return to the same work? How to adapt work and manage fatigue?  
With the participation of: Barbara Mazzolini (Association Française  
contre l'Amylose), Julien Mathias (Association Française contre  
l'Amylose), Julie Pompougnac (Créteil, France)

06:45 pm

### END OF THE FIRST DAY

08:15 pm

### DINNER





# DOCTORS & PATIENTS CHANNEL

## SATURDAY, JULY 6

09:00 - 09:15 am

**REGISTRATION** - Welcome coffee | Visit exhibit

09:15 - 10:45 am

### **SESSION 6** 2024 ISA news

*Chairmen:* **Stefan Schönland** (Heidelberg, Germany),  
**Ben Woltering** (Amyloidosis Alliance, The Netherlands)

- 09:15 Introduction: standards of care in 2024 and current challenges  
Arnaud Jaccard (Limoges, France)
- 09:35 Discussion
- 09:45 **Latest developments in treatment**  
Efsthios Kastritis (Athens, Greece)
- 10:05 Discussion
- 10:15 **New diagnostic tools and technologies**  
Hans Nienhuis (Groningen, The Netherlands)
- 10:35 Discussion

10:45 - 11:15 am

Coffee break | Visit exhibit

11:15 am - 12:45 pm

### **SESSION 7** Treatment management

*Chairmen:* **Nathalie Meuleman** (Brussels, Belgium),  
**Barbara Mazzolini** (Association Française contre l'Amylose)

- 11:15 **The goals of treatment**  
Paolo Milani (Pavia, Italy)
- 11:35 **Potential side effects and how to manage them**
- 12:55 **Why and when to stop the treatment**  
Monique Minnema (Utrecht, The Netherlands)
- 12:15 Discussion



**DOCTORS  
& PATIENTS  
CHANNEL**

**SATURDAY, JULY 6**

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12:45 - 02:00 pm      Lunch time | Visit exhibit

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**02:00 - 02:45 pm      INDUSTRY SYMPOSIUM**

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**02:45 - 04:15 pm**

**SESSION 8**

Treatments in 2024 and beyond

*Chairmen:*      *Frank Bridoux (Poitiers, France),  
Barbara Mazzolini (Association Française contre l'Amylose),  
Ben Woltering (Amyloidosis Alliance, The Netherlands)*

- 02:45      Initial patient-tailored treatment strategy
  - 03:05      Relapse treatment strategy  
Ashutosh Wechalekar (London, Great Britain)
  - 03:25      Ongoing clinical trials  
Ute Hegenbart (Heidelberg, Germany)
  - 03:45      Position of organ transplantations in 2024  
Nelson Leung (Rochester, USA)
  - 04:05      Discussion
- 

**04:15 - 04:30 pm**

**CONCLUSION**

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04:30 pm      **END OF THE MEETING**

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# GENERAL INFORMATION



## VENUE:

nhow Brussels Bloom  
Rue Royale 250  
B - 1210 Brussels  
+32 2 220 66 11  
[www.nhow-hotels.com](http://www.nhow-hotels.com)

## FROM THE BRUSSELS

### AIRPORT:

- Taxi: 30/40 minutes trip
- Public transport: train to Brussels North Station (15 minutes), then 10 minutes walk or 5 minutes taxi ride to the hotel

## FROM THE TRAIN

### OR METRO STATION:

- **Closest train stations:**
  - > Brussels North (850 meters away from the hotel)
  - > From Brussels-Midi station: 15/20 minutes taxi ride or 25 minutes by metro (line 2)
- **Closest metro station:** Botanique

## PUBLIC TRANSPORT:

- Tram 92 and 93: stop Botanique
- Metro line 2 and 6: stop Botanique
- Bus 61: stop Botanique  
[www.stib-mivb.be](http://www.stib-mivb.be)

## LANGUAGE:

Official language: English

Translation available  
(for patients only, in person):  
English/French

## REGISTRATION FEES

|                                            | BEFORE<br>31/05/2024 | FROM<br>01/06/2024 |
|--------------------------------------------|----------------------|--------------------|
| • Doctors                                  | €330                 | €380               |
| • Paramedical professions                  | €120                 | €170               |
| • Fellows / Students *                     | €100                 | €150               |
| • Patients / Association's representatives | €30                  | €50                |
| • Industry                                 | €850                 | €950               |
| • Streaming (only online)                  | €125                 | €175               |
| • Dinner                                   | €70                  | €70                |

\*On presentation of proof

The registration fees include: attendance to all scientific sessions, congress kit, lunches, coffee breaks.

## CANCELLATION POLICY:

Until 10/06/2024: 100% refund with administrative fees of 20 Eur deducted  
From 11/06/2024: no refund

## ACCOMMODATION:

Rooms have been reserved for attendees with special course rates at Hotel nhow. Reservations must be made before June 27, 2024.

<https://www.nh-hotels.com/en/event/international-al-amyloidosis-meeting>

Contact: Alec MIKAILIAN - [a.mikailian@nhow-hotels.com](mailto:a.mikailian@nhow-hotels.com) | +3222206906

REGISTRATION AND INFORMATION:  
[ALamyloidosismeeting.com](http://ALamyloidosismeeting.com)



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**CONGRESS SECRETARIAT:**

32 rue Eugène Olibet - F 33400 TALENCE  
Tél : +33 5 57 97 19 19  
info@comm-sante.com

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