

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

FOR PATIENTS AND DOCTORS



5-6 July, 2024  
BRUSSELS



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

## PROGRAM

ORGANIZED BY:



WITH THE COLLABORATION OF:



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

5-6 July, 2024  
BRUSSELS



# JOIN US IN BRUSSELS!

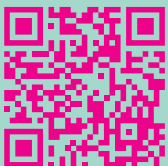
The Amyloidosis Alliance is pleased to welcome you to the first International AL Amyloidosis Meeting, which will be held in Brussels on July 5-6, 2024.

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  
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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  
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Cardiovasculaires,  
Toulouse, France
- **Barbara MAZZOLINI**  
Association Française  
contre l’Amylose, France
- **Prof. Monique MINNEMA**  
Academic Medical Center,  
Utrecht, The Netherlands
- **Drs Ben WOLTERING**  
Amyloidosis Alliance,  
The Netherlands

## SCIENTIFIC COMMITTEE

- **Prof. Antoine BONDUE**  
Hôpital Universitaire  
de Bruxelles, Belgium
- **Prof. Frank BRIDOUX**  
Centre de Référence  
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- **Prof. Thibaud DAMY**  
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- **Agnès FARRUGIA**  
Director of the Amyloidosis  
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Peter MacCallum Cancer  
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- **Prof. Ute HEGENBART**  
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- **Prof. Efstathios KASTRITIS**  
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University of Athens, Greece
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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
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Utrecht, The Netherlands
- **Prof. Giovanni PALLADINI**  
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- **Dr Virginie PASCAL**  
CHU de Limoges, France
- **Prof. Stefan SCHÖNLAND**  
Hämatologie, Onkologie  
und Rheumatologie Zentrum  
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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
- **Drs Ben WOLTERING**  
Amyloidosis Alliance,  
The Netherlands



**FRIDAY, JULY 5**

**DOCTORS  
CHANNEL**

**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), Helen Lachmann (London, GB)**

10:00 **Kidney**  
Lluis 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**

*Chairmen:* **Nelson Leung (Rochester, USA),  
Michelle Michels (Rotterdam, The Netherlands)**

11:50 **Peripheral nervous system**

12:10 **Others: GI, nutrition, hypotension, fatigue, muscle loss, sexual dysfunction**  
Ornella Rizzo (Brussels, Belgium)

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

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

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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**

*Chairmen:*

*Roland Drewinski (Germany), Olivier Lairez (Toulouse, France)*

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?**

Olivier Lairez (Toulouse, France)

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), Helen Lachmann (London, GB)*

11:15

**Kidney**

Lluis Quintana (Barcelona, Spain)

11.30

**Others (malnutrition, macroglossia, dysgeusia)**

Ornella Rizzo (Brussels, Belgium)

11:45

**Dialysis**

Anne-Lorraine Clause (Brussels, Belgium)

12.00

**Cardiac**

Christian Knackstedt (Maastricht, The Netherlands)

12.15

**Peripheral nervous system**

12.30

Discussion

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**FRIDAY, JULY 5**

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01:00 - 02:30 pm Lunch time

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

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**03:00 - 04:30 pm**

**SESSION 3**

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

*Chairmen:* **Ric-Paul Hammink** (Amyloidosis Alliance, The Netherlands),  
**Barbara Mazzolini** (Association Française contre l'Amylose)

- 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**  
Marianna Arvanitaki (Brussels, Belgium)
  - 03:45 **Physical training for amyloidosis patients during the treatment**  
Benjamin DePoorter (Brussels, Belgium)
  - 04:00 **Role of patient's organisation and care givers**  
David Gregory (The Ukpata, Great Britain)
  - 04:15 Discussion
- 

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

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**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**
- 05:30 **Muscular rehabilitation and sport**  
Julien Mathias (Association Française contre l'Amylose)
- 05:45 Discussion

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**PATIENTS  
ASSOCIATIONS  
CHANNEL**

**FRIDAY, JULY 5**

.../...

**06:00 - 06:45 pm**

**SESSION 5**

**Return to work**

*Chairmen: Barbara Mazzolini (Association Française contre l'Amylose),  
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: Teresa Deutsch, Amyloidosis Support Groups (USA), Julien Mathias (Association Française contre l'Amylose), Julie Pompougnac (Créteil, France)

06:45 pm

**END OF THE FIRST DAY**

08:15 pm

**DINNER**





**SATURDAY, JULY 6**

**DOCTORS  
& PATIENTS  
CHANNEL**

**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 Kastiris (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  
Michel Delforge (Leuven, Belgium)
- 12.55 Why and when to stop the treatment  
Monique Minnema (Utrecht, The Netherlands)
- 12.15 Discussion



**SATURDAY, JULY 6**

**DOCTORS  
& PATIENTS  
CHANNEL**

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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),  
Ric-Paul Hammink (Amyloidosis Alliance, The Netherlands),  
Barbara Mazzolini (Association Française contre l'Amylose)*

- 02:45      **Initial patient-tailored treatment strategy**  
Marie-Christiane Vekemans (Brussels, Belgium)
  - 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**
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**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 31/05/2024	FROM 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 | +3222206906

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