

1ST INTERNATIONAL AL AMYLOIDOSIS MEETING

FOR PATIENTS AND DOCTORS



5-6 July, 2024
BRUSSELS



ALamyloidosismeeting.com

PROGRAM

ORGANIZED BY:



WITH THE COLLABORATION OF:



**1ST INTERNATIONAL
AL AMYLOIDOSIS
MEETING**

FOR PATIENTS AND DOCTORS

5-6 July, 2024
BRUSSELS



JOIN US

IN BRUSSELS!

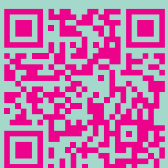
The Amyloidosis Alliance is pleased to welcome you to the first International AL Amyloidosis Meeting, which will be held in Brussels on July 5-6, 2024.

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



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
- **Drs 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**
Amyloïdose Zentrum,
Universitätsklinikum
Heidelberg, Germany
- **Prof. Arnaud JACCARD**
Centre de Référence
Amylose AL, Limoges, France
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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
- **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**

.../...

01:00 - 02:30 pm Lunch time

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

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
-

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

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**

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

.../...

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: **Rick-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 de Poorter (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

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: 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
Efsthathios 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
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**

.../...

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

02:00 - 02:45 pm INDUSTRY SYMPOSIUM

02:45 - 04:15 pm SESSION 8
Treatments in 2024 and beyond

Chairmen: *Frank Bridoux (Poitiers, France),
Rick-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**
-

04:15 - 04:30 pm CONCLUSION

04:30 pm **END OF THE MEETING**

GENERAL INFORMATION



VENUE:

nhow Brussels Bloom
 Rue Royale 250
 B - 1210 Brussels
 +32 2 220 66 11
 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

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

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