

General Assembly 2025



EUROPEAN MULTIPLE ENDOCRINE
NEOPLASIA ALLIANCE

European MEN Alliance e.V. Meeting
12.September 2025

General Assembly 2025

Agenda

General Assembly

16:00 BST / 17:00 MEZ

- Welcome
- Overview of EMENA's activity in 2024/25
- 2024/2025 Funding and Budget Report
- 2026 Year Plan and Budget (and allocation of tasks)
- Date of 2026 General Assembly and call for hosts

General Assembly 2025

Annual Members' Meeting

- EMENA Members' activities 2024/25 presentations
- MEN1 Clinical Practice Recommendations
(Gerlof Valk and team in Rotterdam, Marialuisa Brandi (via Zoom))
- WorldMEN 25 in Brazil (Ronald Damen)

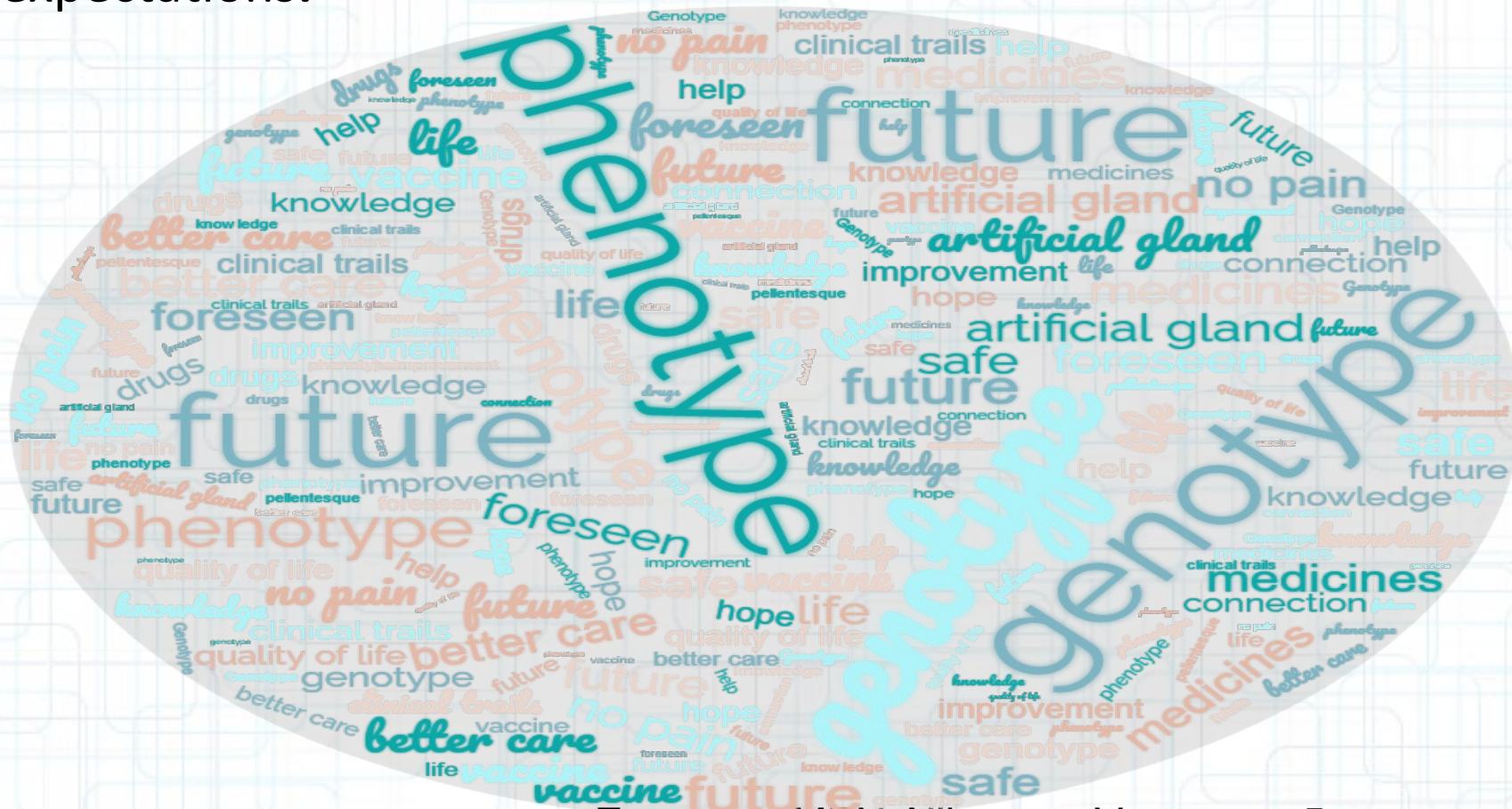
General Assembly 2025

Important aspects from Survey Unmet needs in Germany

- Faster **diagnosis**
- **Awareness** for our rare disease: faster referral to a Center of Expertise through the outpatient health care
- Better **communication** among the different care teams : hospital / outpatient partners
- **Research** : ways for a prediction and prevention of a possible aggressive outcome (for example pNETS). Therefore the inclusion of patients in a database – EuRRECa – is necessary und needs improvement.

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An European database and MEN Patients' expectations:



European MEN Alliance e.V.
Meeting 12.September 2025

General Assembly 2025

Review



For more details see:
www.emena.eu

General Assembly 2025

Review

Survey

Unmet needs – A survey for **European** MEN patients



https://ec.europa.eu/eusurvey/runner/Unmet_needs_MEN_patients_in_Europe_2024

A screenshot of a web-based survey form. The title is "Unmet needs - an EMENA survey for MEN patients". Below the title is a note: "Fields marked with * are mandatory." followed by a small 'x' icon. A disclaimer box follows, stating that the European Commission is not responsible for the content of questionnaires created using the EUSurvey service. At the bottom of the form, there are two logos: the EMENA logo (European Endocrine Network Alliance) and the Endo-ERN logo (European Reference Network on Rare Endocrine Conditions).

A PhD student is currently analyzing the available data set.

General Assembly 2025

Update

EMENA Survey „unmet needs“

Draft ID: af1362ff-086e-406d-99a7-0e5344c0b11e
Date: 08/10/2023 11:16:37

Unmet needs - an EMENA survey for European MEN patients

Fields marked with * are mandatory.

Unmet needs - an EMENA survey for European MEN patients



With this questionnaire we would like to give you the opportunity to tell us how you feel about the current situation with MEN, which things you are happy with and which things you are not. Read the questions carefully.

There are no right or wrong answers. A truthful and complete answer to all questions as well as the demographic information are important for the study.

It takes about 10 to 12 minutes to complete this survey.

The guidelines for good ethical research require that participants in empiric studies explicitly and comprehensibly agree to take part.

Voluntariness: Participation is voluntary and you can be withdrawn at any time.

Anonymity: Your data are of course confidential, will only be evaluated in an anonymous form and will not be passed on to third parties. Demographic data such as age or gender do not allow any clear conclusion to be drawn about your person.

If you are interested in the results, you can voluntarily enter your email address at the end of the survey. You will then receive a summary of the results by email after the survey has been analysed. Your email address will not be stored in connection with your answers.

Thank you in advance for your participation!

If you have any questions, please feel free to contact us by email (Petra.Bruegmann@emena.eu).

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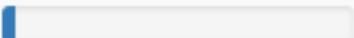
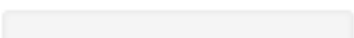
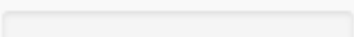
145 answers from different countries

18	United Kingdom
52	Germany
34	Italy
15	The Netherlands
5	Belgium
6	Sweden
3	Spain
2	Ireland
2	Greece

One answer each from
Denmark, Estonia, Hungary and Romania,
three answers from outside EU and UK,
one answer is without country information.

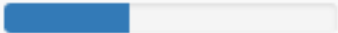

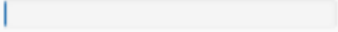
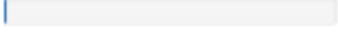
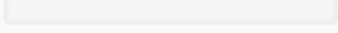
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5. Which MEN syndrome do you have ?

		Answers	Ratio
MEN 1		118	79.45 %
MEN 2a		24	16.44 %
MEN 2b / MEN 3		6	4.11 %
MEN 4		0	0.00 %
No Answer		0	0.00 %

Nearly 80 %
are MEN 1
patients

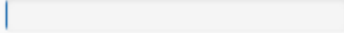
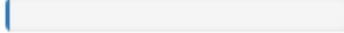
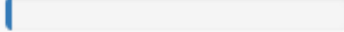
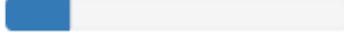

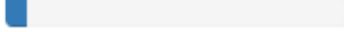
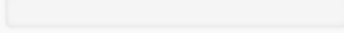
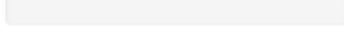
4. What is your gender ?

		Answers	Ratio
male		55	37.67 %
female		89	60.96 %
other		1	0.68 %
I don't like to answer.		1	0.68 %
No Answer		0	0.00 %

61 %
female


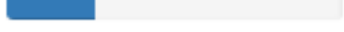
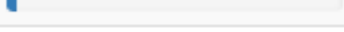


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3. What is your age?

		Answers	Ratio
0 - 4		1	0.68 %
5 - 12		2	1.37 %
13 -18		3	2.05 %
19 - 39		28	19.18 %
40 - 65		103	70.55 %
66 - 80		9	6.16 %
over 80		0	0.00 %
No Answer		0	0.00 %

About 70 %
are at the age
of 40 to 65


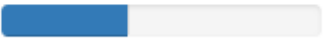
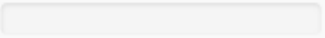
2. Are you a patient or parent/carer?

		Answers	Ratio
Patient		97	66.44 %
Patient and parent of a child with MEN		38	26.03 %
Parent or caregiver answering for a minor child		5	3.42 %
Partner or family member		6	4.11 %
No Answer		0	0.00 %

And patients
(67 %)


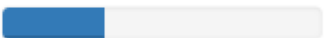
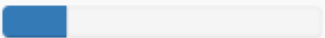
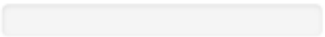
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21. Do you know any Centers of Excellence in your country ?

		Answers	Ratio
Yes		88	60.27 %
No		58	39.73 %
No Answer		0	0.00 %


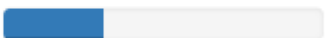
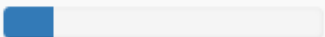
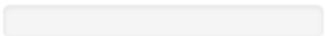
Nearly 40 % know no Center of Excellence in their country.

22. Are you treated at a Center of Excellence ?

		Answers	Ratio
Yes		69	47.26 %
No		47	32.19 %
I don't know		30	20.55 %
No Answer		0	0.00 %

Nearly 53 % can't say for sure they are treated at a Center of Excellence

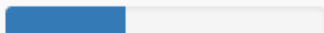
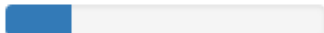
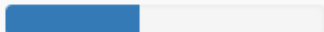
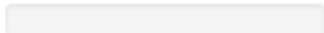
20. Is a multidisciplinary team (MDT) involved in your care?

		Answers	Ratio
Yes		77	52.74 %
No		46	31.51 %
I don't know		23	15.75 %
No Answer		0	0.00 %

Only 53 % are treated form a multidiciplinary team (MDT)


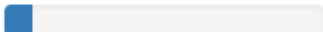
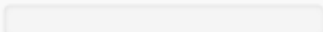
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16. Are you already registered in a MEN research database?

		Answers	Ratio
Yes		55	37.67 %
No		30	20.55 %
I don't know		61	41.78 %
No Answer		0	0.00 %



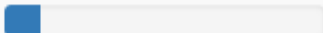
Only 38% are aware that they are registered

17. Are you interested in sharing and accessing your medical data on a MEN research database ?

		Answers	Ratio
Yes		133	91.10 %
No		13	8.90 %
No Answer		0	0.00 %

However, over 91% are interested in sharing and accessing their medical data in a MEN research database

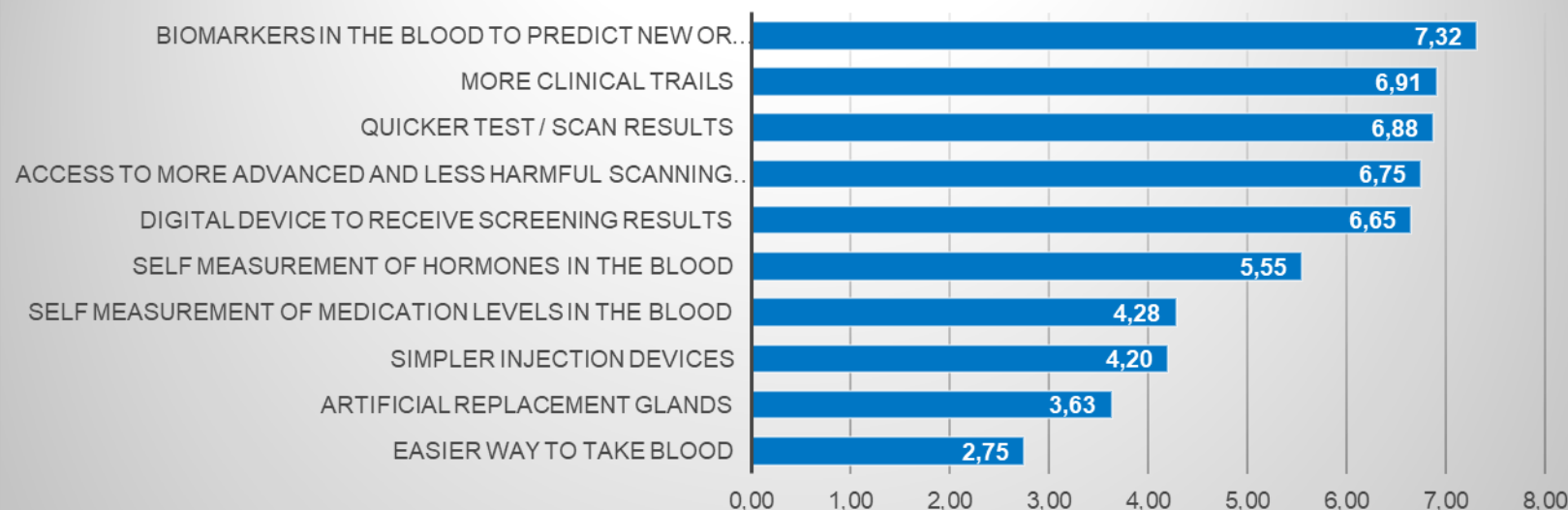
17a. Are you interested in what your medical data is being used for?

		Answers	Ratio
Yes		123	84.25 %
No		7	4.79 %
No Answer		16	10.96 %

84% are interested in how their data is used

General Assembly 2025


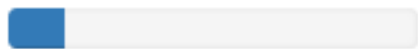
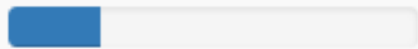
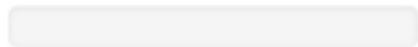
Ranking of unmet needs



- 7.32** **Biomarkers in the blood to predict new or recurring tumours**
- 6.91 More clinical trials
- 6.88 Quicker test / scan results
- 6.65 Digital device to receive screening results
- 6.75 Access to more advanced and less harmful scanning /imaging
- 5.55 Self measurement of hormones in the blood
- 4.28 Self measurement of medication levels in the blood
- 4.2 Simpler injection devices
- 3.63 Artificial replacement glands
- 2.75 Easier way to take blood

General Assembly 2025

33. Is there a patient advocacy group in your country you know of ?

		Answers	Ratio
Yes		93	63.70 %
No		20	13.70 %
I don't know		33	22.60 %
No Answer		0	0.00 %

Spain

Our task:

We need to get in touch with the patients in Spain, France, in the Nordic region and in Eastern Europe !

We need to raise awareness for the MEN-disease !

We need to promote registries !

We need to foster Research programmes and funding !

General Assembly 2025

Review



We are involved in the creation and distribution of a patient questionnaire on the subject of "Drug and medicines shortages", which is also distributed to the national professional associations of the ESE and ESPE.

Here is still the link:

https://ec.europa.eu/eusurvey/runner/MedicineShortagesPatientenVersion07_24

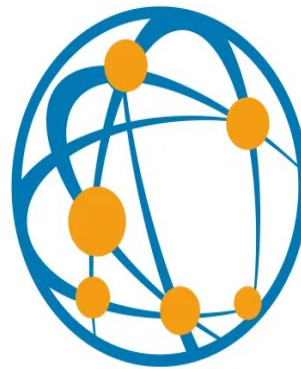
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- funded by the European Union's Health Program
- launched in 2018
- aimed at maximising the opportunity for patients, health care professionals and researchers to participate and use high-quality registries.
- includes an e-reporting programme (e-REC) and a core registry, that collects a common dataset and clinician and patient reported outcome.

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The MEN module -
similar to the
parathyroid module -
will be added.
The test draft is under
construction.



EuRRECa
European Registries For
Rare Endocrine Conditions

General Assembly 2025

Review

- We are an eligible member of the EUROPEAN MEDICINES AGENCY (EMA)

www.ema.europa.eu

Eligible patients and consumers
organisations



General Assembly 2025

Review

As a member of EURODIS and the COUNCIL of EUROPEAN FEDERATIONS we are in good contact to different patient groups and collect their experiences and expertise.

They suffer from the same problems: the financial issue and the language problem to get in touch with Eastern European Countries.



General Assembly 2025

Review



Osteoporosis is a condition that we usually get for free, especially in MEN 1 patients, when the diagnosis has been many years in coming. In order to help make these connections even clearer, we are grateful to Prof. Brandi for bringing us into contact with the IOF. We have become a member (for free).

General Assembly 2025

Membership Update

We didn't manage to involve some more European groups. We are still in contact with families in Spain and Greek.


But they still didn't manage to set up legalized patient groups.

How can we manage to involve them?



General Assembly 2025

Financial and Budget 2024/25

	
Geschäftsgirokonto 41110875 BLZ 250 501 80	Kontoauszug 5
Sparkasse Hannover UST-ID DE115648383	Blatt 2
Datum Erläuterungen	Betrag
01.08 Abrechnung 31.07.2025	13.903,94+
siehe Anlage Nr. 1	2,00-
Übertrag in Wert: 01.08.2025	

Kontostand in EUR am 05.08.2025, 09:27 Uhr	
Kontostand kann Beträge mit späterer Wertstellung enthalten, s. Rückseite	
Anzahl Anlagen 1	
Aktuelle Wertstellung +13.901,94 EUR	

DuraLeaf Optima
Der Umwelt zuliebe

Europäische Allianz für Multiple Endokrine Neoplasien



13.901,94€

There are no income positions besides the membership fees. The expenses related to notary fees and registration in the register of associations, as well as the ongoing costs of two euros per month for the bank account.

It can be assumed that this amount will increase in 2026.

General Assembly 2025

Financial Report 2024/2025

1. Auditor's Report and Advice

The cash auditors propose to the Annual General Meeting that the Management Board be fully relieved.

(see written Report by Prof. Dr. Ludwig Schaaf and Helga Schmelzer)

General Assembly 2025

Auditor's report



Auditor's Report / Kassenprüfung

Report on the examination of the association's treasury
EUROPEAN MEN ALLIANCE e.V. Munich,
For the period from 01.07.2024 to 31.07.2025.

1.
According to Article 15 of the Articles of Association, a cash audit for each year of two examiners. The signatories to this minutes were appointed as cash auditors at the Annual General Assembly on September 30, 2016.
2.
On 31.07.2025, the auditors carried out the cash check for the period from 01.07.2024 to 31.07.2025
3.
The following documents were available for the examination:
 - a.
Account statements to the Account at the Stadtparkasse Wunstorf, Kontonummer DE 82 2515 2490 0014 110875 (changing with 01.06.25 to Stadtparkasse Hannover DE84 2505 0180 0041 1108 75 without gaps

Presented from extract no. 3/2024 to extract no. 05/2025


- b.
The booking journal
The computerized bookkeeping with totals and balance lists
- c.
Minutes of the Annual General Assembly and Board meetings.
4.
The test was carried out partly by random sampling.
5.
This is the 09th cash check.
6.
The cash balances and contests of the annual report are in accordance with the balances of these account statements.
7.
All income and expenses were recorded correctly. Proper documents were available.
8.
There were no complaints within the audit.
9.
The cash auditors propose to the Annual General Meeting that the Management Board be fully relieved.

31.07.2025
Prof. Dr. Ludwig Schaaf

Helga Schmelzer

General Assembly 2025

Financial Plan and Budget 2026

			
Geschäftsgirokonto 41110875 BLZ 250 501 80		Kontoauszug	5
Sparkasse Hannover UST-ID DE115648383		Blatt	2
Datum Erläuterungen		Betrag	
01.08 Abrechnung 31.07.2025		Übertrag in EUR	13.903,94+
siehe Anlage Nr. 1		Wert: 01.08.2025	2,00-
Kontostand in EUR am 05.08.2025, 09:27 Uhr			13.901,94+
Kontostand kann Beträge mit späterer Wertstellung enthalten, s. Rückseite			
Anzahl Anlagen	1		
Aktuelle Wertstellung	+13.901,94 EUR		

DuraLeaf Optima
Der Umwelt zuliebe

Europäische Allianz für Multiple Endokrine Neoplasien



13.901,94 Euro

Up to now we paid 24 € / year bank fees, but due to changes there will be an increase next year.

General Assembly 2025

Financial Plan and Budget 2026

Besides the membership fees there are no incoming payments.

It is to be expected that there will be again no financial support from Eurordis next year.

Bank account 01.08.25	13.901,94 €	
	Income	Expenditure
Membership fees	1.000,00 €	
Grants, Donations	0,00 €	
Travel costs / Eurordis GA Meeting Grant	0 €	
Fees (bank, notary fees, registry)		1.000,00 €
MEN Recommendations: Translation/Publishing		8.000,00 €
Reserve		4.901.94 €
Total		13.901,94 €

General Assembly 2025

Tasks 2025/2026

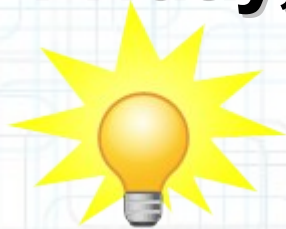
- What can EMENA do for your Organisation in 2025/2026 ?
- What are your barriers to involvement ?
- Strategic Planning meeting arrangements
- Dissimilating the survey
- New members
- Translation of MEN 1 Recommendations
- Push the European MEN registry within EuRECCa



General Assembly 2025

Invitation General Assembly 2026

 **Friday, 16.October 2026**



Online
Germany ?
United Kingdom ?
Italy ?
The Netherlands ?
Belgium ?

General Assembly 2025

Annual Members' Meeting

- EMENA Members' activities 2023/24 presentations
- MEN1 Clinical Practice Recommendations
(Gerlof Valk and team in Rotterdam, Marialuisa Brandi (via Zoom))
Discussion / translation / working group
- WorldMEN 25 in Brazil (Ronald Damen)

General Assembly 2025

Network pituitary and adrenal disorders

2024/25

Several online meetings

Annual meeting f2f in october in Berlin
including a special **MEN session**

Leaflets updated and new leaflets published

- Representation of the network at the **German regulatory authority for medicines** (benefit assessment, pricing)
- Collaboration in the framework of the **German Association for Rare Diseases** to establish the structures for German reference networks analogous to the European ones.
Unfortunately still difficult, not only with regard to endocrinology due to missing legislation and funding.
- Poster presentation „National Conference on Rare Disorders“



General Assembly 2025

German MEN
Meeting,
11.October 2025
in Berlin, Charité

Workshops (Parallelworkshops) (nur mit Anmeldung, Teilnahme ist begrenzt, die Anmeldung erfolgt nach Eingangsdatum)	
14.30–15.30	Workshop 1 (Hörsaal 3) Nebennieren-Insuffizienz – wie Hydrocortison anpassen? <i>Dr. med. Tina Kienitz</i>
14.30–15.30	Workshop 2 (Seminarraum 523) AGS – von der Kindheit bis zur Transition <i>Dr. med. Uta. Neumann</i>
14.30–15.00	Workshop 3-1 (MEN) (Seminarraum 520) Multiple Endokrine Neoplasie 1 – Chirurgische Aspekte: Wann und wie den primären Hyperparathyreoidismus und wann und wie gastrointestinale NETs operieren? <i>PD Dr. med. Martina Mogl</i>
15.00–15.30	Workshop 3-2 (MEN) (Seminarraum 520) Multiple Endokrine Neoplasie 2 – Diagnostik, Therapie und Familienbetreuung <i>Prof. Dr. med. Holger Willenberg</i>
15.30–16.00	Kaffeepause
16.00–17.00	Workshop 3-3 (MEN) (Seminarraum 520) Multiple Endokrine Neoplasie 1 – Internistische Aspekte: Neue Empfehlungen bezüglich MEN 1 <i>Prof. Dr. med. Ludwig Schaaf</i>
16.00–17.00	Workshop 4 (Hörsaal 3) Endokrinologische Hormondiagnostik und Tests <i>Dr. med. Katharina Lang</i>
16.00–17.00	Workshop 5 (Seminarraum 523) Therapiekonzepte der Adipositas <i>Dr. med. Nina Meyer</i>

General Assembly 2025

Poster
National
Conference
For Rare
Disorders,
September 2025
in Berlin



Unerfüllte Bedürfnisse und Lebenszufriedenheit von MEN-Patienten im deutschsprachigen Raum

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Methoden

Das Netzwerk für Hypophysen- und Nebennierenerkrankungen e.V. hat eine bundesweite Umfrage zu den ungedeckten Bedürfnissen von Patienten mit multiplen endokrinen Neoplasien (MEN) in Deutschland durchgeführt. Ziel der Studie war es, ungedeckte Bedürfnisse in Bezug auf Versorgung und Lebensqualität sowie potenzielle Verbesserungsmöglichkeiten zu identifizieren. Die Umfrage basierte auf einem Fragebogen, der von der European MEN Alliance e.V. (EMENA) entwickelt wurde, einem Zusammenschluss europäischer Patientengruppen und Ärzten, die Familien betreuen, die von Erkrankungen mit MEN betroffen sind. Die Umfrage wurde von der deutschen Patientenvertretung über die EU-Umfrageplattform der Europäischen Kommission unter Gruppenmitgliedern, Ärzten und in sozialen Medien verbreitet. Insgesamt wurden 73 Antworten ausgewertet.

Resultate

Erkrankungen

54 Fälle von MEN1, 10 Fälle von MEN2A, 6 Fälle von MEN2B und 4 Fälle von MEN4 wurden ausgewertet.

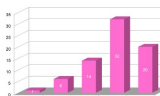


Geschlechterverteilung

64 % der Befragten waren weiblich.



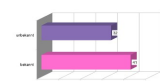
Mehr als die Hälfte aller Befragten war zwischen 40 und 60 Jahre alt (62,1 %) und fast alle wurden nach dem Auftreten von MEN-assoziierten Tumoren mit einem positiven genetischen Mutationsnachweis diagnostiziert (90,8 %).



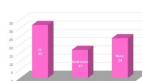
In welchem Lebensalter wurde die Diagnose gestellt?

Die meisten Diagnosen wurden im Lebensalter zwischen 19 und 39 Jahren gestellt.

Behandlung in einem Kompetenzzentrum und Einbeziehung eines multidisziplinären Teams (MDT)

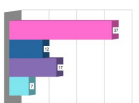


Kennen Sie ein Kompetenzzentrum?



Ist ein multidisziplinäres Team in Ihrer Versorgung einbezogen?

Etwa 20 % der Befragten waren sich nicht sicher, ob ein MDT an ihrer Behandlung beteiligt war.



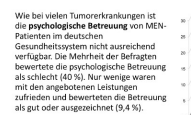
Etwa 40 % bewerten die Kommunikation zwischen den Fachkräften und dem Hausarzt als schlecht.

Zugang zu Endokrinologie-Assistentinnen

Nur 27 % der deutschen Befragten bewerten den Zugang zu Endokrinologie-Assistentinnen als gut oder sehr gut. 35 % kennen keine Endokrinologie-Assistentin.



Wie bei vielen Tumorerkrankungen ist die psychologische Betreuung von MEN-Patienten im deutschen Gesundheitssystem nicht ausreichend verfügbar. Die Mehrheit der Befragten bewertete die psychologische Betreuung als schlecht (40 %). Nur wenige waren mit den angebotenen Leistungen zufrieden und bewerteten die Betreuung als gut oder ausgezeichnet (9,4 %).



Biomarker zur Erkennung und Vorhersage möglicher Tumorrezidive haben höchste Priorität, wenn es um unerfüllte Bedürfnisse bei der Behandlung von MEN-Patienten geht. Darüber hinaus wünschen sich Patienten und ihre Familien schnellere Screening-Ergebnisse und weitere Forschung zu dieser Erkrankung. Moderne Bildgebungsverfahren und Verbesserungen bei der Selbstmessung von Hormon- und Medikamentenkonzentrationen stehen ebenfalls auf ihrer Wunschliste.



Sind Sie in einer MEN-Forschungsdatenbank registriert?

29 (39,1 %) der Befragten sind in einer MEN-Forschungsdatenbank registriert. Nur fünf der Befragten sind nicht daran interessiert, in eine Datenbank aufgenommen zu werden. 39 Befragte sind daran interessiert, ihre Daten für ein Register zur Verfügung zu stellen, sind jedoch noch nicht registriert.



Schlussfolgerungen

Weitere Forschungsprojekte im Bereich der MEN sind notwendig, um die gewünschten Verbesserungen für bisher ungedeckte Bedürfnisse zu erreichen. Die MEN-Patienten nannten mehrere ungedeckte Bedürfnisse: An erster Stelle standen Biomarker zur Vorhersage neuer Tumoren oder Rezidive, an zweiter Stelle weitere klinische Studien. Diese Verbesserungen können nur erreicht werden, wenn ausreichend Daten (und in Zukunft Biobanken) verfügbar sind. Die Mehrheit der MEN-Patienten ist bereit, ihre Daten für die Forschung zur Verfügung zu stellen, aber sie nehmen diese Möglichkeit nicht praktisch wahr, zumindest in Deutschland, wie die Umfrage zeigt. Auf der Grundlage dieser Ergebnisse besteht die wichtigste zukünftige Aufgabe von Patientenvertretungsgruppen darin, mehr Wissen und Informationen über die digitalen nationalen und internationalen Vernetzungsstrukturen und die Bedeutung von Registern für die Versorgung und Forschung unter den Ärzten, Mitgliedern, betroffenen Patienten und Familien zu verbreiten und sich als Patientenvertreter zu engagieren.

Nur mit Hilfe von Registern können wir die Bedürfnisse von MEN-Patienten erfüllen.



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Achievements 2023/24 and goals 2025

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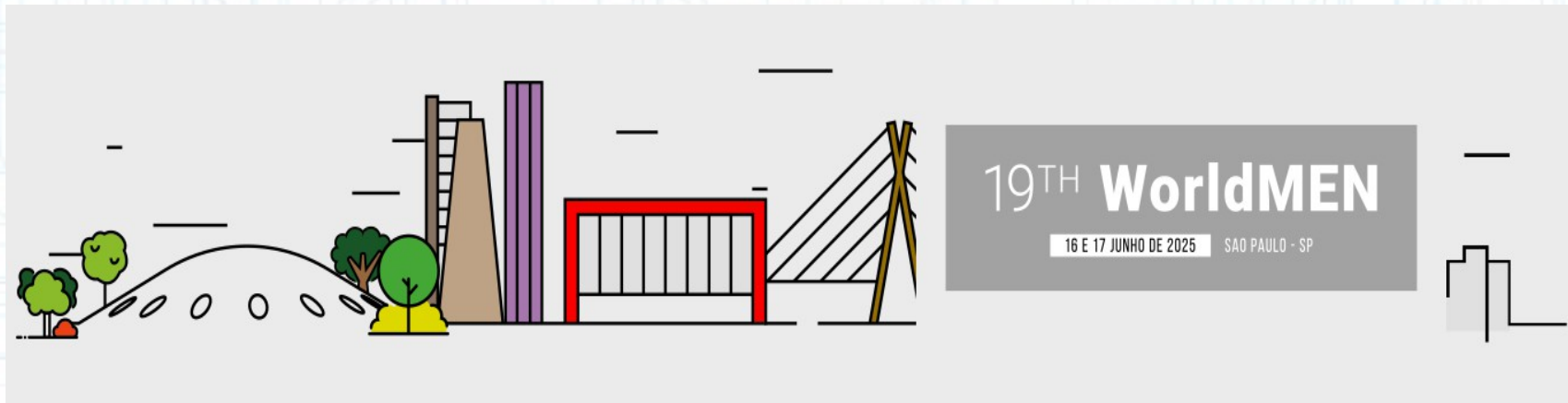
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Sao Paulo 16./17.june 2025



Ronald Damen 's report .

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Recommendations
MEN 1 are
published



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THANKS



Especially THANKS to the belangengroep MEN for hosting us in Rotterdam !!!!!!!!!!!!!