



EKHA General Assembly

June 28, 2022

Annex 1

Presentations of the new EKHA members

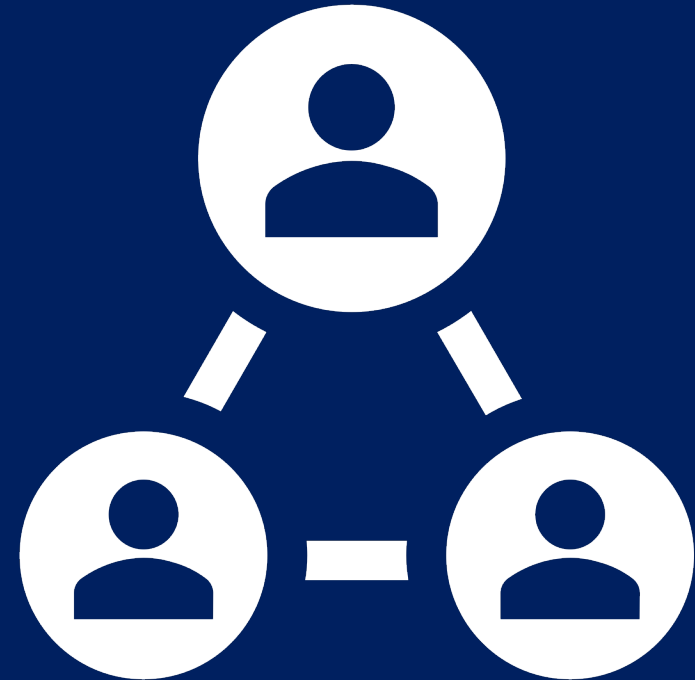
Introduction of new members:

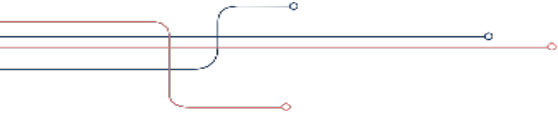
NVBN, Greek society of Nephrology, KfH

Kuratorium für Dialyse, Renaloo

Hungarian Society of Nephrology, Swedish

Society of Nephrology , Eutox, GNFB





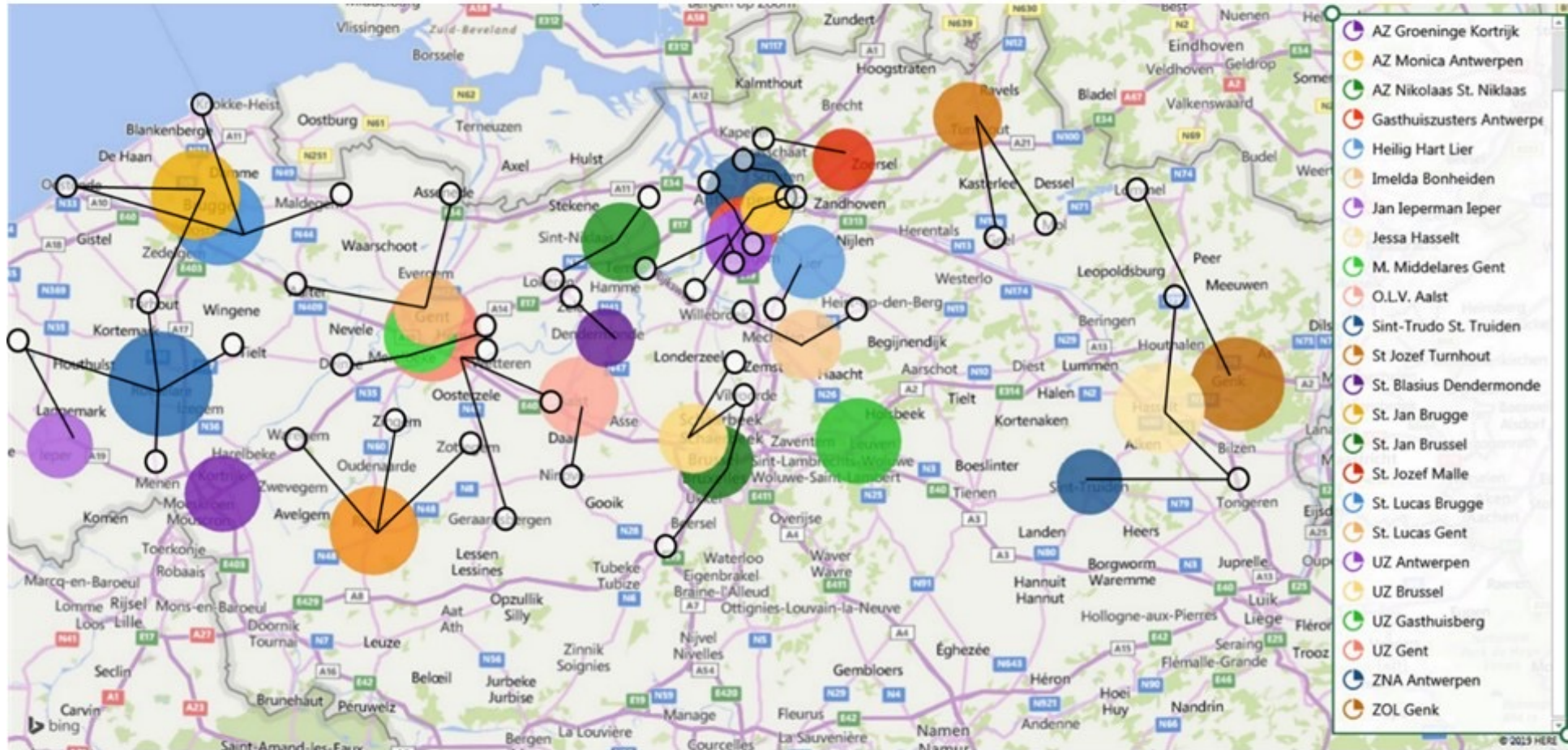
EKHA General assembly : Presentation of NBVN

28-06-2023



NBVN : who are we ?

- 
- NBVN = Nederlandstalige Belgische Vereniging voor Nefrologie
 - Belgian Association of Dutch-speaking Nephrologists, representing :
 - Dutch-speaking Nephrologists from Flanders and Brussels Capital Region
 - 27 Nephrology centers in Flanders + Brussels Capital Region
 - GNFB : our French-speaking counterpart
 - BVN-SNB : Belgian society : more research-oriented





NBVN : 2022 mission statement

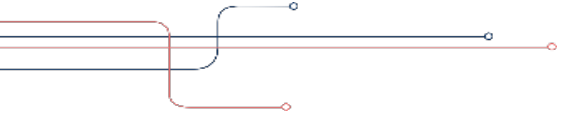


Our goal is to promote nephrology in the broadest sense of the world with emphasis on 4 key missions :

- 1.To conduct clinical scientific research, with the direct goal to improve clinical outcomes and the quality of life of the nephrologic patient
- 2.To contribute to keep her members scientifically up to date and to ensure that her members practice medicine according to the highest clinical standards and to the benefit of patients.
- 3.To protect the professional interest of her effective members
- 4.To contribute to the promotion of public awareness around the societal burden of kidney disease



What do we do ?

- 
- CORN database of dialysis in the Flanders Region
 - Incidence and prevalence
 - Distribution of modalities
 - Demographics
 - Survival statistics
 - Reports for national government + ERA-EDTA registry, together with our colleagues from GNFB
 - FCGG = Flanders collaborative group on glomerulonephritis : database of kidney biopsies
 - Request for approval for initiating clinical trials has been submitted to authorities
 - Public awareness campaign for WKD 2023 (together with GNFB)

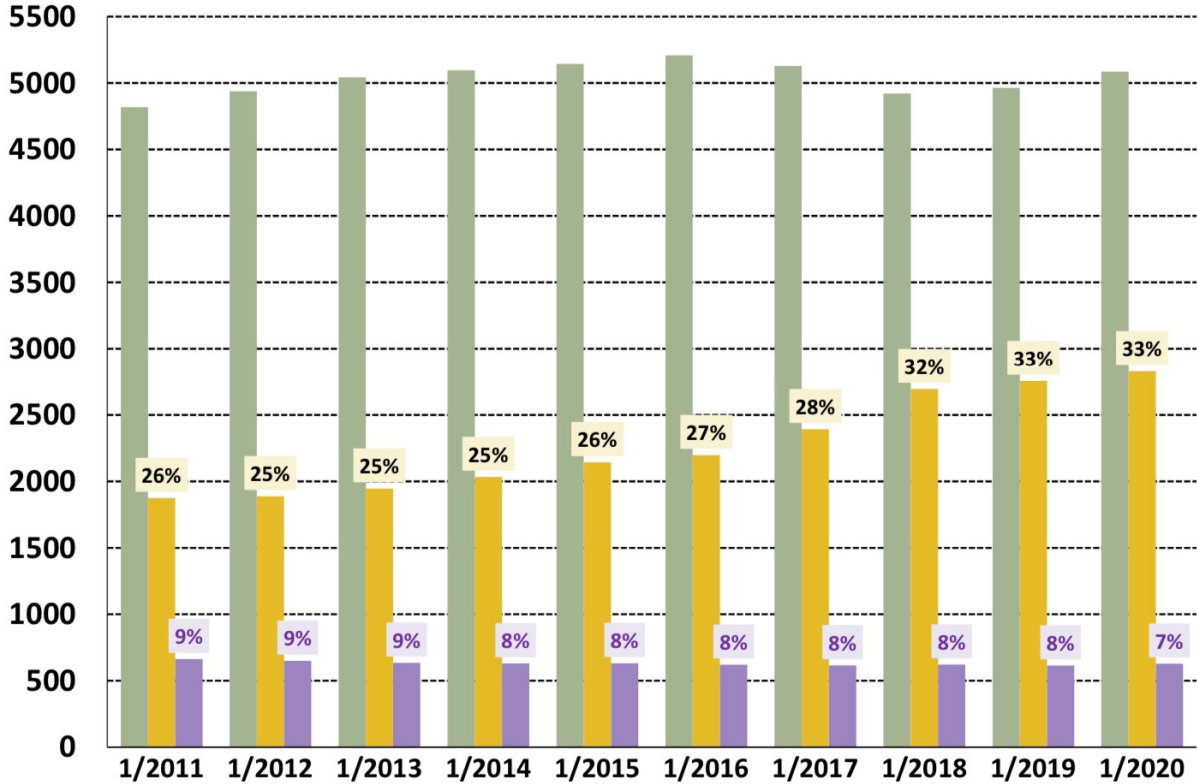
The CORN +GNFB dialysis registry



Collège de médecins




Jan 2011 - Jan 2020



- Hemodialysis - High Care
- Hemodialysis - Low Care (day/night, home, selfcare)
- Peritoneal dialysis

Total number patients living on dialysis on 1 January	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
	7357	7478	7624	7760	7920	8029	8139	8240	8335	8537



NBVN-Lentemeeting

Donderdag 16 maart 2023

Ter Elst

Awareness campaign World Kidney Day 2023





NBVN and EKHA

- NBVN shares common goals with EKHA
 - Increasing awareness in the public
 - Recognition by lawmakers of CKD as a major health issue
 - Correction of underfunding compared to other disease
 - Design of (pragmatic) clinical trials to fill the knowledge gaps in daily practice
 - Support for early detection and screening

- We hope to make a small but meaningful contribution to

Thank you for your attention





[World Kidney Day Campaign](#)



HELLENIC SOCIETY OF NEPHROLOGY

Dimitrios Petras, MD, PhD

President



HELLENIC SOCIETY OF NEPHROLOGY

- Hellenic Society of Nephrology (HSN) was founded in 1970 & is the official representative of medical field of nephrology in Greece
- Members are only nephrologists (340 Nephrologists & 88 residents in Nephrology)
- Aims are the contribution to:
 - Prevention strategies of kidney diseases in Greece
 - Preparing guidelines for evidence-based treatment of kidney diseases in Greece
 - Research on kidney diseases in Greece
 - Keeping registries of specific kidney diseases in Greece
- Coordinating educational courses for the residents in the specialty of Nephrology



HELLENIC SOCIETY OF NEPHROLOGY

- HSN is responsible for continuous medical education in the field of Nephrology organizing:

- Educational courses
- Scientific meetings
- Webinars
- The national nephrology congress every year
- HSN participates/co-organizes scientific congresses with other scientific societies
- HSN has established grants for young nephrologists
- HSN yearly organizes scientific and social events on World Kidney Day
- HSN is publishing a scientific Journal every 4 months

KfH* Kuratorium für Dialyse und Nierentransplantation e. V.

For the patient.

* H = formerly „Heimdialyse“ (Home dialysis)

Nationwide KfH network

KfH in 2022 - Overview



18.056

Dialysis patients

71.511

Clinic patients

169

KfH kidney centres

26

KfH medical care centres

17

KfH kidney centres for children and young people

6.118

Members of staff

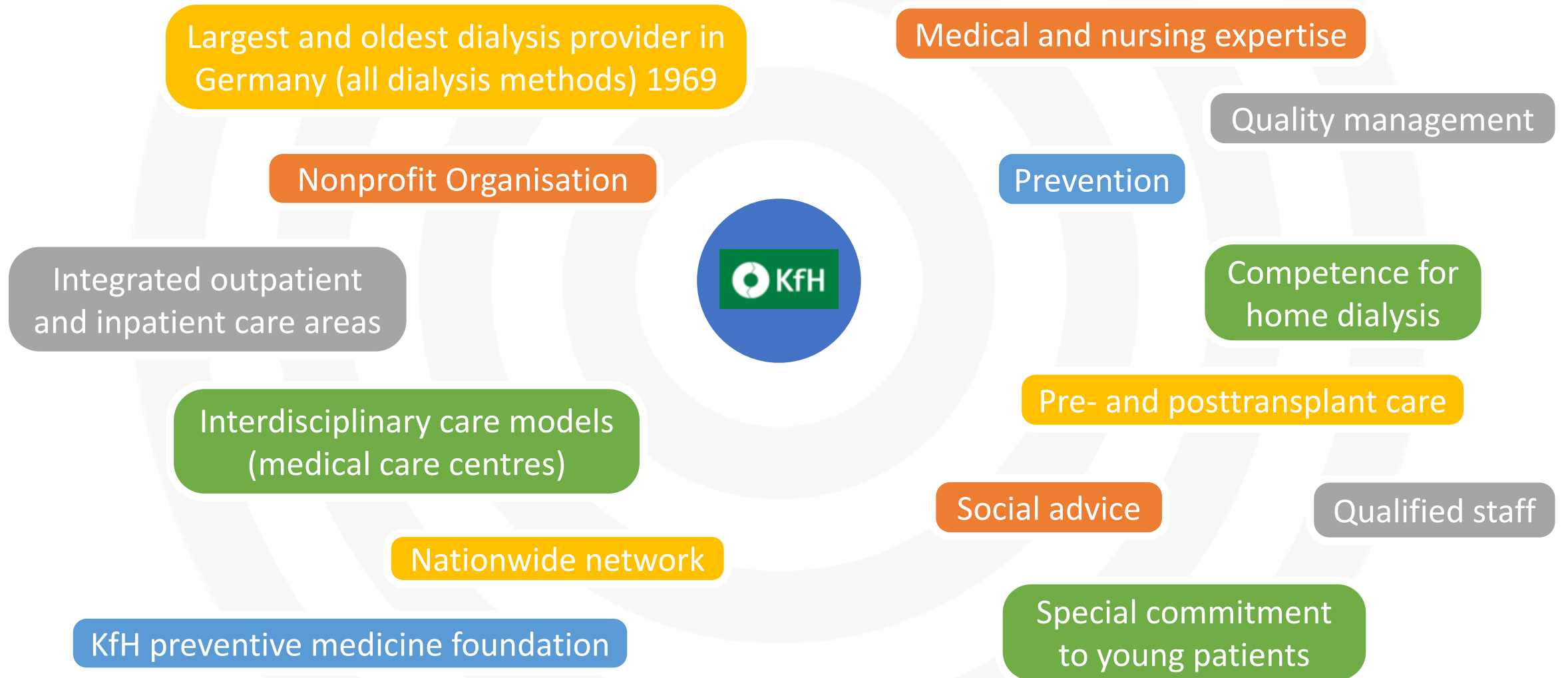
7

Logistics centres



KfH. For the patient.

Integrated Nephrological Care



Renaloo

A French patient organisation

Renaloo's History

- Renaloo was created 21 years ago
 - By Yvanie Caillé, who is now Vice-President
 - Lack of information for kidney patients
- Web-based (renaloo.com)
 - Started as a blog
 - Became a registered organisation in 2008



The screenshot shows the Renaloo website interface. At the top, there's a navigation menu with links like 'Accueil', 'Rechercher', 'Forum', 'Livre d'or', 'Contact', 'à propos', 'Plan du site', and 'Don d'organes'. The main content area features a testimonial from a user named 'Nouvelles' (dated 14/09/2009) about kidney transplantation. The testimonial text reads: 'En septembre 2001, alors que j'avais 28 ans, j'ai appris que ma fonction rénale s'était détériorée de façon importante, et que la dialyse était devenue nécessaire à ma survie. Ce fut le début d'un long et difficile chemin, qui devait aboutir le 31 mai 2002 à une transplantation rénale à partir d'un rein de ma maman.' Below the testimonial, there are sections for 'Lire mon témoignage', 'Découvrir les témoignages de personnes concernées par l'insuffisance rénale, la dialyse ou la greffe', and 'Publiez vos propres témoignages sur Renaloo'. The sidebar on the left contains various widgets like 'Mon histoire', 'Lectures', 'Outils', and 'De site vers a plus?'. The sidebar on the right contains 'LES THÈMES...', 'En dialyse', 'La greffe', 'Après la greffe...', 'Les médicaments', and 'Vos droits'.

Strong digital presence

Renaloo en quelques chiffres



+ 8 000
membres de l'association



+ 5 500
followers Twitter



1 600
visites par jour sur renaloo.com



+ 5 000
membres du groupe Facebook



1 500 réponses et accompagnements personnalisés chaque année

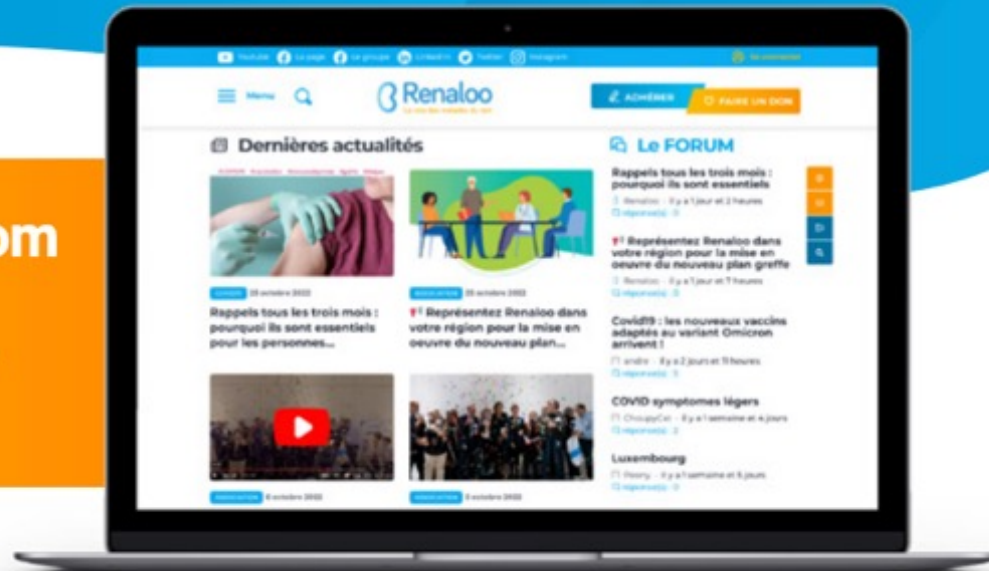
Twitter, Facebook, LinkedIn, Instagram, etc.

Expert patient information

Informier, soutenir,
répondre aux besoins
« Savoir c'est pouvoir »

www.renaloo.com

Une information experte
sur les maladies rénales,
les traitements et la vie
qui va avec.



Regular news mailings, Webinars, Cafés, Forum...

Knowledge-based organisation

- Patients' involvement in the production of data and information
- Renaloo's survey platform, [MoiPatient](#)
 - Registered in 2019
 - Does surveys for Renaloo and other patient organisations

Renaloo, créateur de connaissances nouvelles, issues des patients eux-mêmes

Renaloo mène régulièrement des enquêtes auprès des patients, qui permettent de mettre en lumière leurs expériences, par exemple :



La « **grande enquête des États Généraux du Rein** », à laquelle 9.000 patients ont participé et qui a donné lieu à plusieurs études et publications, notamment sur l'activité professionnelle, et sur les inégalités sociales dans l'accès à la greffe, publiée dans la revue Population en 2016.



Des enquêtes en partenariat avec d'autres associations de patients, comme « **Vivre avec des médicaments antirejet** », destinée à tous les patients greffés d'organes, en 2019/2020.



L'enquête en trois volets « l'expérience des malades des reins durant la crise Covid » a notamment fait l'objet d'une publication dans le prestigieux *British Medical Journal* : "Covid19 et maladies rénales : il est temps d'écouter les patients"

Very strong Advocacy

Renaloo participe de façon très active à la démocratie en santé et aux évolutions du système de santé, à la sensibilisation continue des pouvoirs publics sur les enjeux des maladies rénales, avec un objectif unique :
améliorer la qualité des soins et de la vie.



Notre plaidoyer, nos combats

Des actions concrètes et un plaidoyer construit et argumenté

- › Priorité à la greffe
- › Accès à une dialyse de qualité et choisie : autonome, à domicile, quotidienne, nocturne, etc.
- › Lutte contre les inégalités d'accès aux traitements
- › Décision partagée
- › Accès à l'innovation
- › Qualité de vie, accès aux droits, maintien dans l'emploi, assurance emprunteur, etc.

Promotion of patients' rights and access to better treatments, including transplants

Some of Renaloo's achievements

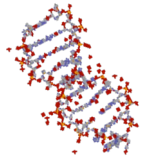
- 2011: Revision of the French bioethics law > Possibility to donate a kidney to a friend
- 2012-13: Renaloo organises « les états généraux du rein » > Transversal awareness
- 2017-18: The President announces the reform of kidney care funding system
- 2021: Priority access to Covid vaccines & treatments > immunocompromised patients
- 2022: Ambitious & well funded 4th plan on organ transplants

Renaloo's EU advocacy

- 2021: Start of Renaloo's European strategy
 - Becomes a member of EKPF
 - Develops recommendations together with EKHA, France Rein and SFNDT in view of the French Presidency of the EU (Jan-June 2022)
- 2022: Renaloo contributes to the development of the project PREVENT CKD
- 2023: Renaloo becomes a member of EKHA & EPHA



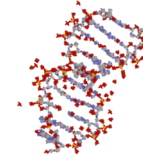
Thank you for your attention !



EKHA annual General Assembly 2023

June 28, 2023 / 10.00 – 14.00 CEST

Rue de La Presse 4, 1000 Brussels



Introduction of the Hungarian Society

Prof. emer. Dr. Laszlo Rosivall

President



Institute of Translational Medicine
International Nephrology Research and Training Center
Semmelweis University
Avicenna International College
Tehran University of Medical Sciences

Hungarian Society of Nephrology

Presidents, 1977-



István Taraba

**23th EDTA-EDTA
Congress**

1986



Sándor Sonkodi

1st Basic Science Symposium (1986) of ERA-EDTA Congress

Intrarenal Renin-Angiotensin system

László Rosivall



Judit Nagy



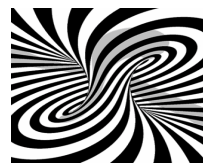
Sándor Turi



György Reusz

**56th ERA-EDTA
Congress**

2019





2023. június
Számunk tartalmából:

A magyar vesebeteg kezelései 2020. évi jelentés az ERA-EDTA Regiszterek

Ami az esszéírókról az idős, hypertóniás beteget gondosan ellátó orvosnak tudnia kell

Út a szívhez a vesén át. A residuális cardiovascularis rizikó csökkentésének újabb törlője

A MAÉT Országjárás Programjának eredményei

Újdonságok a rendellenes kiválasztási vényrendszer-monitorozásában: fókuszban a mandzsetta nélküli technikák

Dezpresszióval csökkenthető a polycythaemia által okozott nephrogen diabetes insipidusban

Még egy csepp interakció

Kiadja: **30** évet ünneplő Magyar Hypertonia Társaság és Magyar Nephrológiai Társaság

Society's Activity / Committees of

- **Science** (grants, awards, congresses, etc)
- **Education** (gradual, postgradual, CME)
- **Clinical Training** (guidelines)
- **Nursing** (education, research, congresses)
- **Nephropathology** (research, diagnosis, etc)
- **Dialysis** (guidelines, research, etc)
- **Home Hemodialysis** (protocol to start)
- **Transplantation** (cooperation)
- **Psychonephrology** (for support)
- **Rehabilitation** (special emphasis)
- **Epidemiology** (to analyze the changes)
- **Registry** (for ERA, ISN and home)
- **Foreign Affairs** (regional, international)
- **Public education** (for the whole society)
- **Youth** (to support the next generation)
- **History** (research, education)
- **Ethics** (if needed)

Society's bimonthly periodical together with the Society of

Foundation: 1998
Hypertension

number of copies: 1,800 length:
48+4 pages



Interactive website
for the members
and the
whole society

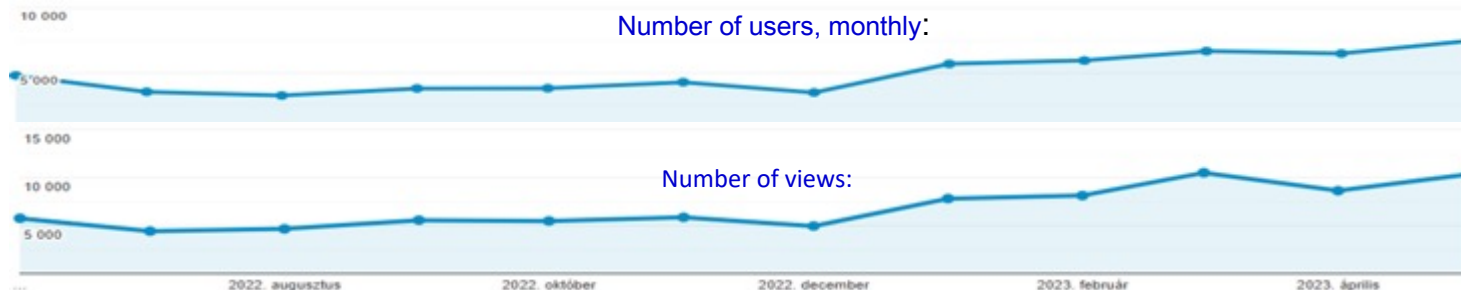


Visits during the last year:
Examined period: 01.06.2022 –
31.05.2023

Total page views: 82,117

Total visits: 71,938

Number of visitors: 55,877





THE 27TH BUDAPEST NEPHROLOGY SCHOOL

Nephrology, Hypertension, Dialysis, Transplantation, Nephropathology

28 August - 2 September, 2023

Held at Semmelweis University with a highly distinguished international faculty, the Budapest Nephrology School is one of the most well-known refresher courses in the field of nephrology. It attracted many young physicians from Europe and around the world (68 countries) since 1993.

Features:

- Nephrology course with diverse topics, including: electrolyte disorders, glomerular physiology and pathophysiology, transplantation, nephropathology, tubular diseases, chronic kidney disease, hypertension
- Lectures from leading experts of nephrology: Jens M. Titze, Friedrich C. Luft, János Pesti-Peterdi, Sotiris Zarogiannis, Csaba P. Kövesdy, Georgina Gyarmati, Zoltán Prohászka, András Tislér, Simin Goral, Jan Becker, Pontus B. Persson, Helderman J. Harold, Kálmán Tory, György Reusz, Miklós Zsolt Molnár
- "Meet the Professors" - an informal meeting during which participants can discuss their experiences and observations with the faculty
- A poster session which aims to have the participants discuss and consult their own research with the faculty

- Participation fee (1450 € until June 30) includes:

- Attendance at the nephrology refresher CME course,
- Certificate of Attendance
- Social programs, wine tasting
- Refreshments, lunches and dinners
- Evening Cruise on the Danube
- Sightseeing Tour with a visit to the Hungarian Parliament
- Farewell Reception

For further information, grants and registration please visit us at

<http://www.hns-hungary.hu>

<http://www.facebook.com/hnsHungary>

<http://twitter.com/BpNephrology>



László Rosivall, MD, PhD, DSc

Professor of Pathophysiology

Semmelweis University, Institute of Pathophysiology

Nephrology Research and Training Center

Nagyváradi tér 4, 1009 Budapest, Hungary

Ph: +361-2100-100; Email: rosivall.laszlo@med.semmelweis-univ.hu

CME course from
26 years

Participants:
from 68
countries so far!



MAGYAR
NEPHROLOGIAI
TÁRSASÁG





SÁNDOR von KORÁNYI
(1866–1944)

Korányi was the first in:

- Measuring **urine osmotic activity** by freezing point depression
- Using **urinary concentration** / dilution probe
- Coined the term “**Renal Insufficiency**” and characterized it functionally (1938 Volhard)

His molecular view on CKD

“If we would be able to control the diet of kidney diseased patients in such a way that the number of molecules produced by the metabolism would not exceed the remaining molecular excretion capacity of the kidney then we would do a world of benefit for the patients.”





Korányi's holistic approach

About illness (1928): „.... illness is not just that of an organ, nor can it be determined from the state of a single organ of the individual, it is the sum of **what the individual thinks** about it, of **what he feels** about it, of the morphologically ailing organ's present and future consequences for other organs, and of how all this **translates into bodily and spiritual suffering.**”

We have to take care of patients' all troubles and:

- + what they think
- + what they feel
- + body's sufferings
- + all spiritual sufferings

It requires a complex team work!



Our view on the role of health / nephrology care

Health and Economics

Direct effects and / or indirect effects, interactions

(sick society ↔ sick economy ↔ sick population)

Increase of life expectancy by 1 year → GDP 4% ↑

Increase of disability-free life by 1 year → GDP 11% ↑

How about the decrease of incidence of CKD? → ???

Health Care is the maintenance of the most important means of production i.e. the human power

Doctors / Nephrologists are the Key Players of Economy
Medicine is the Key Segment of the Economy

My recommendation to the IFKF, 2003

I think it is time and it is our duty to call for the attention of the nations, governments and statesmen to announce and support a Day or a “Week of KIDNEY”.

This international event should happen in all the countries at the same time addressing the same issues from public level to the professionals employing all the available means like media, open days in universities or dialysis centers, lectures, distribution of flyers etc, to increase the public awareness and attract more support for Nephrology. It is possible that in some of the more developed countries they have similar projects, but this international movement will increase the power of the Foundations and will ultimately benefit the renal

My recommendation to the EKHA, 2023

It is the time to call for the attention of everybody, that every day should be a Kidney Day, i.e. everyone in anytime should take care of his/her kidneys.

Education on renal function, GFR should happen in all the countries worldwide addressing the same issues from public level to the professionals employing all the available means like **politicians, EU**, media, open days in universities or dialysis centers, lectures, flyers, twitter, facebook, etc, to public and increase the awareness and knowledge on Nephrology.

Relief from the tomb of Tepemākh (Djadjaemankh), ca. 2700 to 2200 BCE. Louvre Museum, Paris, France.



Kidneys are among the list of **funerary offerings**; it is shown in the boxed hieroglyph.

The importance of the kidney, history

Kidneys in the Bible

The „kidneys” used to signify the center of feeling, awareness, such as joy or pain (Job 19: 27; Isa.11: 5; Rev. 2: 23).

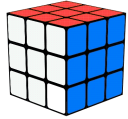
Jeremiah 17:10.

I the Lord search the heart, I try the kidneys, even to give every man according to his ways, and according to the fruit of his doings.

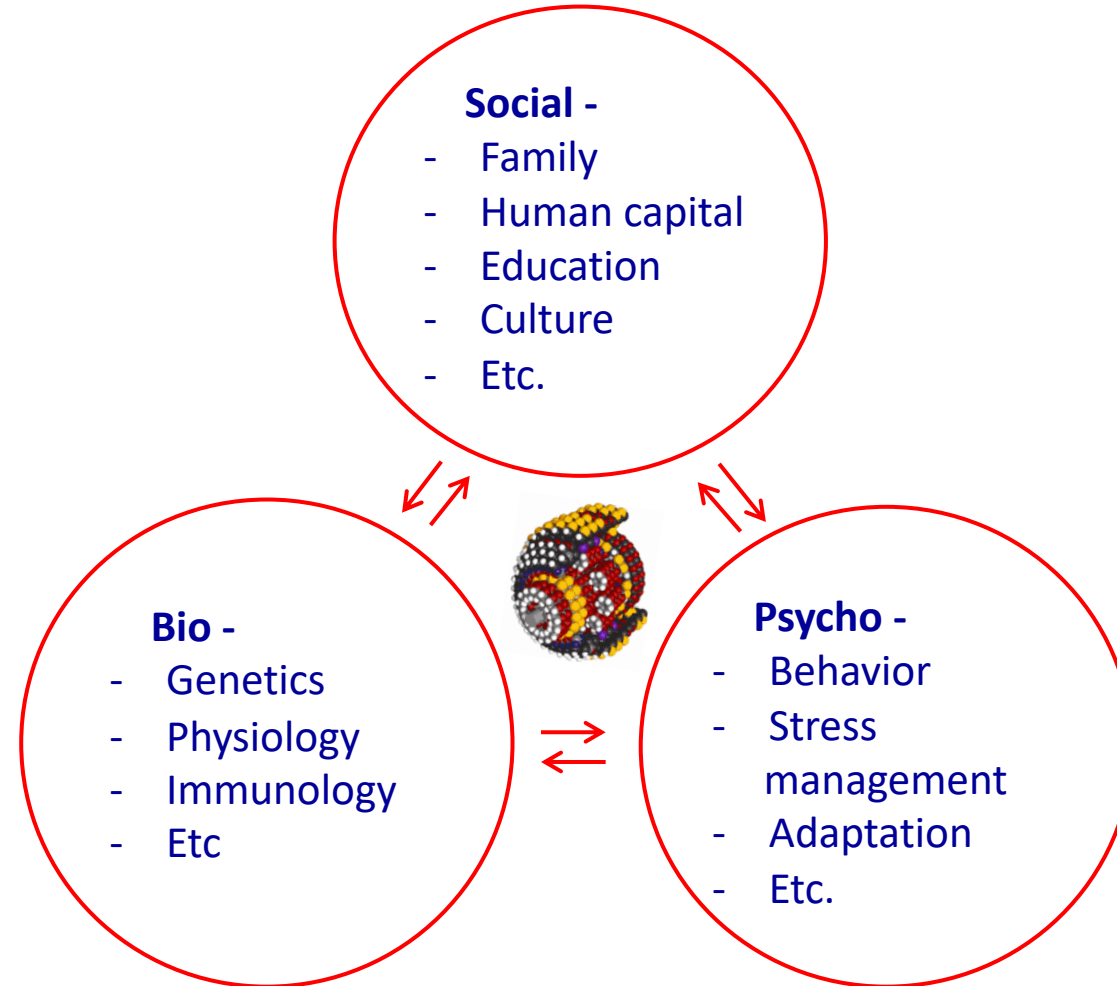
Psalms 26:2

Examine me, O LORD, and prove me; try my kidneys and my heart.

**In Chinese and Japanese medicine in middle age:
Kidney is the Gate of Life, Gate of Vitality, Yin and Yang**



Coin has two sides - Life and disease have three!



Which is the primary event in a disease!?

New horizons in Medicine/Nephrology

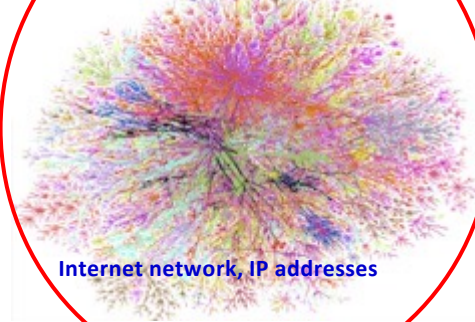


Erdős, Pál and Rényi, Alfréd



(a) Random network

Social, f.e...:



Internet network, IP addresses

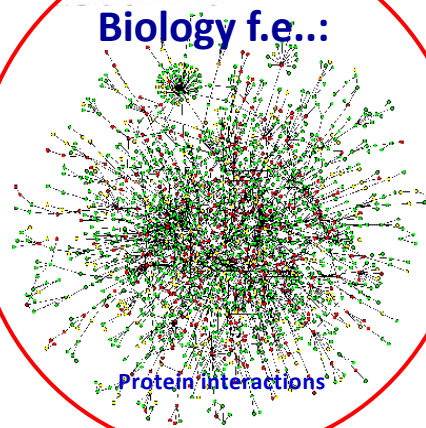


Barabási, Albert László



(b) Scale-free network

Biology f.e...:

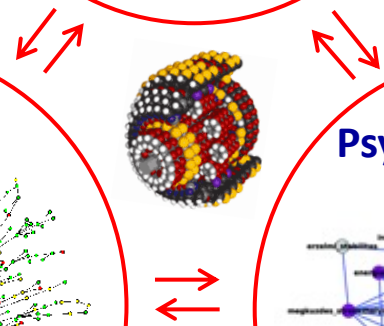
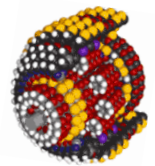


Protein interactions

Psychology, f.e.:



Psychogalaxy projekt

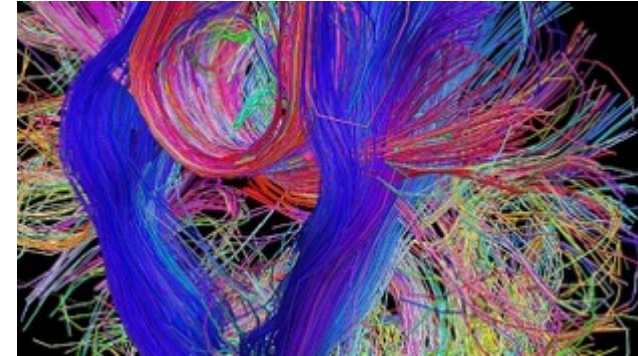


There are networks behind every phenomenon

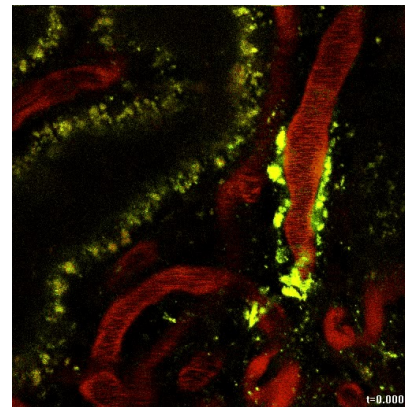
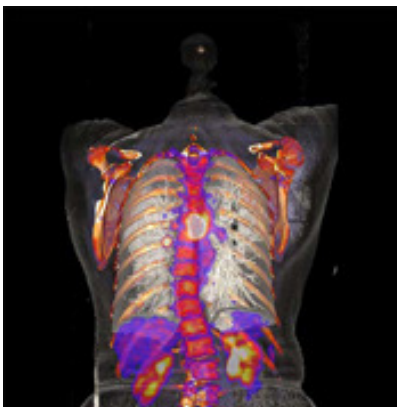
The future medical science, new dimensions, challenges, thinking, Functional network and visualization



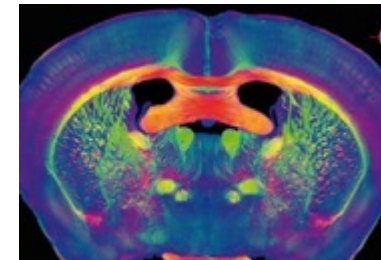
A diffusion spectrum image shows the brain wiring in a healthy human adult



The Human Connectome Project is giving neuroscientists a new perspective on the connections in the brain and how they communicate with each other



Imaging renal filtration in a living animal - Rosivall, 2006





THE 2012 BUDAPEST DECLARATION OF THE IFKF

- „.....employ a holistic approach for the treatment of patients living with chronic kidney disease, recognizing **all their bio-psycho-socio-spiritual and somatic needs.**”
- „.....focusing on the whole person and individual care to ensure better efficacy in the **prevention, treatment and rehabilitation.**”

All these about the prevention only and just even a part of that!

The 2012 Budapest Declaration of the IFKF

A holistic approach to address the
bio-psycho-socio-spiritual needs of individuals
living with chronic kidney disease

<http://ifkfbudapest.com>

Patients' possibilities, self management



Live with renal failure

Handbook for patient to prevent and self management

written by

Kerstin Bergström és Per Åke Zillén

Translated by

Kiss Gergely

Edited by

Prof. Dr. Rosivall László

Semmelweis Press , 2012

Hungarian Kidney Foundation ensures free of charge access
(<http://vese-alapitvany.hu/hu/betegtajekoztato/>)

Education and life style camps for patients and their relatives in Diósjenő



The only „requirement”: **bring one of the relatives!**
Kálmán Polner, Ágnes Haris

A Dream of Patients Became Reality

In 1989 a small private enterprise called **Nephrocentrum Medical Care Group** was established in form of a cooperative by 16 kidney patients.

THE AIM OF THIS GROUP: was to establish a modern dialysis unit, operated by the patients themselves where – after a rehabilitation process – they could also have a job.

OCTOBER 1991: the NEPHROCENTRUM FOUNDATION WAS ESTABLISHED



Another way of physico-psycho-social rehabilitation of patients with RRT



Two young patients on CAPD organized a Bike tour in 2012

There aim to prove:
patients on RRT may live healthy,
active, high quality life

Around lake Balaton, 210 km, 4 days

6 pts, 4 nurses, 1 nephrologist, 16 friends

RenBike Tour 2014

- 27 patients, **270** participants, 35 km around lake Velencei
- Later on around lake Balaton again, with great success, 28 patients, **147** participants



Active sporty life of RRT patients



What else we wish to achieve?!

**Do not be afraid
to think unthinkable thoughts!**
Together we are going to change the presence!

Let's go and start!
There is still a lot to do
for decreasing the CKD incidence
worldwide!

The only way to have a better future:

Education

Education

Education

Education

Education



**Take
Home
Message**

**Tour du table for
updates from other
affiliated members**





10-point plan to intensify home dialysis use

Andreas Kribben

Past-President of the German Society of Nephrology

10-point plan to intensify home dialysis use



- 1** Standardized educational materials in simple language covering all options of renal replacement therapy, including kidney transplantation, as an integral part of the quality system guideline
- 2** Involve patient organizations
- 3** Ensure that all dialysis procedures are performed during specialist training and continuing training, with concomitant adjustment of the Specialist Training Regulations

10-point plan to intensify home dialysis use



- 4 Opportunities to perform all forms of inpatient and outpatient renal replacement therapy during specialist training
- 5 Extend telemedicine to intensify home dialysis use
- 6 Ensure adequate reimbursement for all types of dialysis
- 7 Introduce a National Kidney Plan and a Disease Management Program for chronic kidney disease

10-point plan to intensify home dialysis use



- 8 Support of kidney transplantation: Optimize organ donation by informing citizens better and by improving and reviewing clinical processes
- 9 Introduce a Dialysis Register to record the quality of treatment
- 10 Establish a German Centre of Kidney Diseases (DZNK)

Croatian Society of Nephrology, Dialysis and Transplantation

For all who may be interested in the Croatian program for screening of CKD here is a link to a website(<https://lamedico.eu/BubreznaFunkcija2.php>).

In our experience it is very useful for our GP's. It is in Croatian language, but you can use google translate. Soon ,we are going to upgrade this program.

ZDRAVLJE BUBREGA ZA SVE
SPREMNOST NA NEOČEKIVANO,
PODRŠKA RANJIVIMA!

PROVJERI SVOJU BUBREŽNU FUNKCIJU

Svjetski dan bubrega™
9. OŽUJAK 2023

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Hrvatsko društvo za nefrologiju dijalizu i transplantaciju Hrvatskog liječničkog zbora
KoHOM koordinacija hrvatske obiteljske medicine
HDND
HZJZ

Ukoliko želite odrediti stadij Vaše kronične bubrežne bolesti (KBB), zaprimiti preporuke i savjete o daljnjem postupanju, unesite tražene podatke. Obvezni podaci za unos su spol, godine starosti i vrijednost kreatinina. Vrijednost urinarnog albumin/kreatinin omjera i vrijednost 24-satne mikroalbuminurije su opcionalne. Aplikacija automatski vrši validaciju upisanih vrijednosti traženih podataka i izvjestiti će Vas u slučaju nepravilnog unosa i/ili nepravilnog podatka. Stoga je mogućnost pogreške svedena na minimum. Izvršena analiza umjetnom inteligencijom je isključivo informativnog karaktera. Hvala što ste s nama.

Osobe visokog rizika za KBB

- Oboljeli od šećerne bolesti
- Oboljeli od povišenog krvnog tlaka
- Osobe s prekomjernom tjelesnom težinom
- Oboljeli od strukturalnih bubrežnih poremećaja (ciste, kamenci i sl.)
- Oboljeli od sistemskih bolesti koje mogu zahvatiti bubreg (sistemski lupus eritematodes i sl.)
- Osobe s anamnezom bubrežnih bolesti u obitelji
- Osobe s nasljednom bubrežnom bolesti
- Osobe koje primaju potencijalno štetne lijekove ili supstance za bubreg