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First Things First! Priority for Patient Preferences

CONFERENCE PAPER · AUGUST 2015

1 AUTHOR:



Fokko Pieter Wieringa

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First Things First!



PRIORITY for Patient Preferences



Dr. F.P Wieringa

- Technical Advisor commissioned by the Dutch Kidney Foundation & Dutch Kidney Patient Association
- Member IEC workgroup on world-wide safety standards for Dialysis Equipment
- TNO Shared Innovation Program



KIDNEY HEALTH INITIATIVE

"Understanding Patients' Preferences: Stimulating Medical Device Development in Kidney Disease"

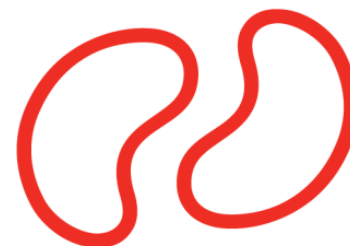
KHI-Workshop, August 12 & 13, 2015 Baltimore Maryland, USA



Dutch Kidney Patient
Association



2014 NVN Document
Free PDF on internet



Dutch Kidney
Foundation

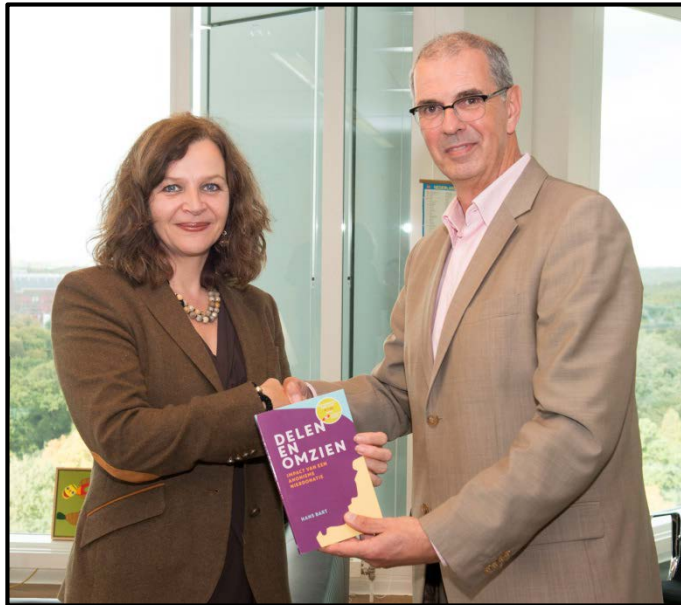


Dutch Kidney Patient
Association

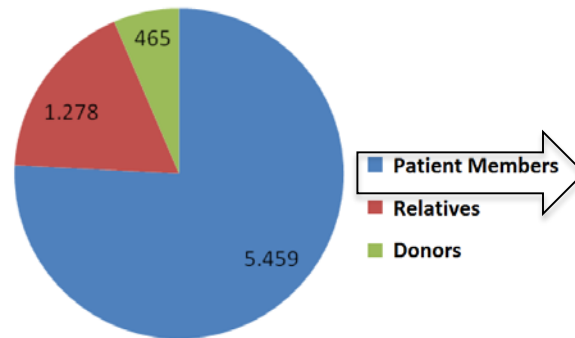
By & for: Kidney patients,
Relatives and Donors

- 7500 members
- 18 staff
- 150 volunteers

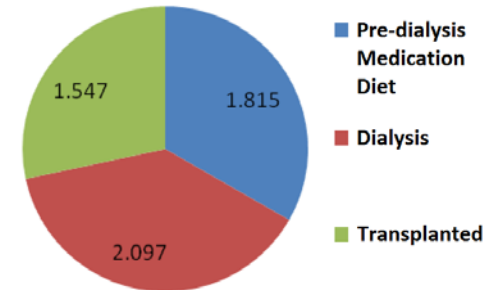
Sets research agenda



Membership NVN



Treatment Types
Patient Members



In 2016 NVN organizes a research symposium
for members & researchers: **You are welcome!**



Dutch Kidney Foundation

Founded 1968
60 employees
75.000 volunteers
€ 21 million raised in 2014
Shares office with NVN



BENEFIETCONCERT VOOR DE NIERSTICHTING
 ZO 18 MEI 2014, 15.00 UUR GROTE KERK NAARDEN



Utrechts Conservatorium Kamerorkest
 o.l.v. Rembrandt Zegers

Steun dit initiatief!
 Kijk voor een een videopresentatie op www.voordekunst.nl
 Kaarten a €15,- zijn te reserveren via www.nierstichting.nl/benefiet



Wolfgang Amadeus Mozart
 Hoboconcert in C majeur, KV 314

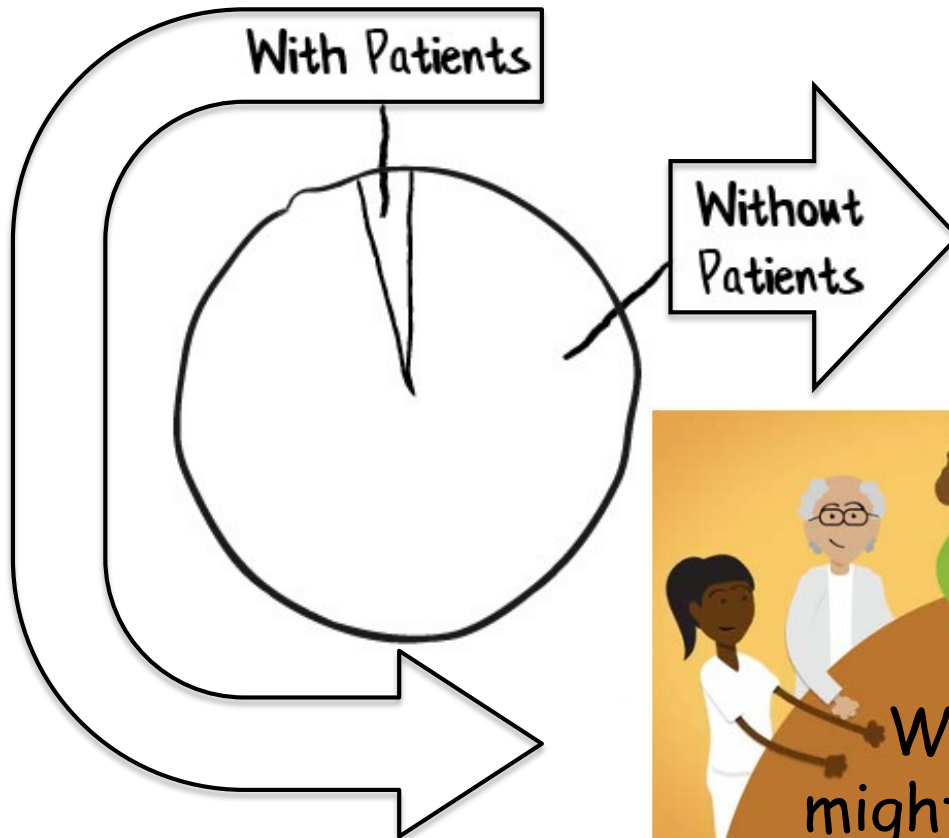
Arvo Pärt
 Fratres voor viool, strijkorkest en slagwerk

Johann Sebastian Bach
 Concert voor hobo, viool en strijk orkest BWV 1060R in d klein



What experience learns:

% of Time Spent Discussing
the Needs of Patients in Healthcare



Go to those that really use it!

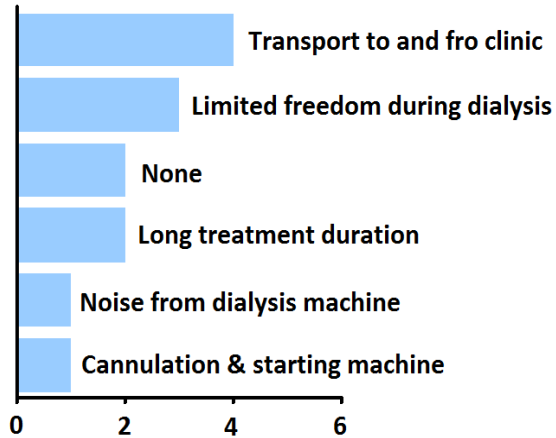


information

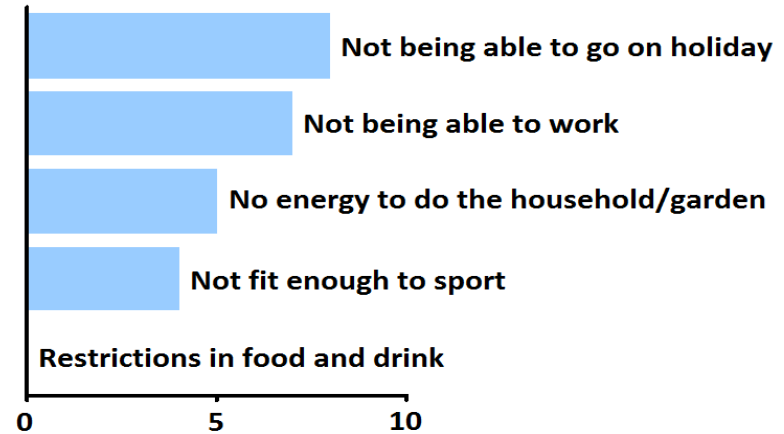


Input received from patients

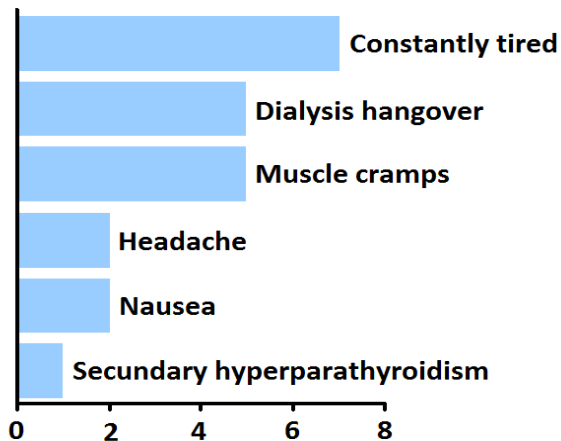
Disadvantages present therapy



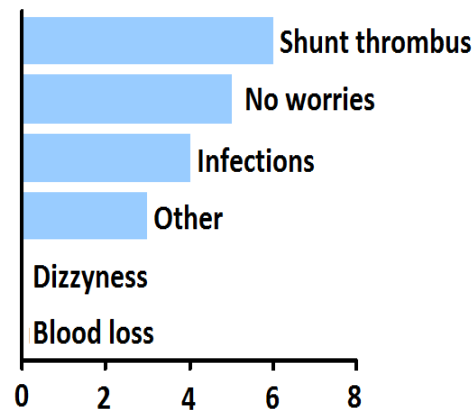
Experienced limitations



Health complaints



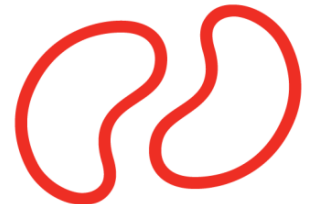
Worries about present therapy



We decided to get going, and invest in Patient Preferred Priorities



Dutch Kidney Patient
Association




Dutch Kidney
Foundation

Straight for wearable HD?



- Several concepts & tests
- A surprising patient preference was found...

→ Wearable HD later →

Portable HD: 2017 → NEOKIDNEY 

- For **HD**: wearable perceived impractical (but wearable **PD** regarded as realistic)
- Preference “suitcase kidney”, freedom to travel
- E.g. dialyse at night and be free during the day

The ideas for WAK and PAK are not new. But with new materials and technologies the realization of practical user friendly devices is coming into reach.



1976 Dr. Friedman



1976 Dr. Kolff



2007 Dr. Gura

Influencing factors therapy choice

1. Remaining independent
2. Being able to cope with demands of chosen treatment
3. Being able to manage treatment

An exploration of the choices of patients with chronic kidney disease,
S. Keeney & H. McKenna, Patient Preference and Adherence **2014**:8 1465–1474



“Getting back my own life”
is common theme in the
wishes of dialysis patients

What's recommended in the EU?



Recommendations for Sustainable Kidney Care

Alliance of non-profit organizations representing Patients, Nephrologists, Researchers & Healthcare Workers

- Prevention & Early detection
- Better choice of treatment
- Increase access to transplantation
- Patient centered reimbursement strategy

Promotion of home dialysis and self care:

- Less need to travel between home and clinic.
- Improves chance on work, sense of freedom and independence to manage own life.
- Those dialysing at home, especially at night, often feel better and have more energy during the day.

World-Wide now ongoing:



- Establish Core outcome set to be consistently measured and reported in haemodialysis research trials.
- Improve integrity, transparency, usability and contribution of research relevant to patients requiring haemodialysis
- Ensure that outcomes of relevance to patients, caregivers, and health professionals, are consistently reported across trials.
- Focus groups with patients on haemodialysis and caregivers to identify, rank, and describe reasons for **their choice** of outcomes
- Stakeholder interviews with patients, caregivers, nephrologists, nurses, allied health professionals, researchers & policy makers

Easier comparison of treatments, including Patient Point of View

<http://songinitiative.org/>

How can we move forward ASAP?



EU “Home use” regulatory (1)

- Pay more attention to user faults, use by lay persons and home specific risk factors in design, risk analysis, and user info
- Collect field experiences more actively, use these for product improvement and secure coherence between risk analysis and user information → Sounds like “*talk more to patients*” to me...

Medical technology at home. International Journal of Technology Assessment in Health Care, 29:1 (2013), 20–26.

EU “Home use” regulatory (2)

- Notified bodies (certifying for EU market) should monitor whether manufacturers have addressed the previous aspects
- If additional user manuals are issued by institutions that support and supervise a specific therapy, these should be drawn up in cooperation with the manufacturer

Medical technology at home. International Journal of Technology Assessment in Health Care, 29:1 (2013), 20–26.

2014 Dutch government report combined desk & field study



1. Quote of patient: *“Largest risk of home technology? When I will **not** receive it”*
2. *“Quality of life deserves more attention”*
3. *“More attention needed for beneficial aspects of home treatment (in general) and not just focus on risk. Patient autonomy is very important, we are willing to accept certain risks when for us the benefits far outweigh them”* → Sounds as “be more *Patient Centric*”...
4. *“Remote judgement PD skin port condition useful”*

Risks of complex medical technology situated within the home.

RIVM report 2014-0061 (Dutch Language, translation of dialysis related parts available)



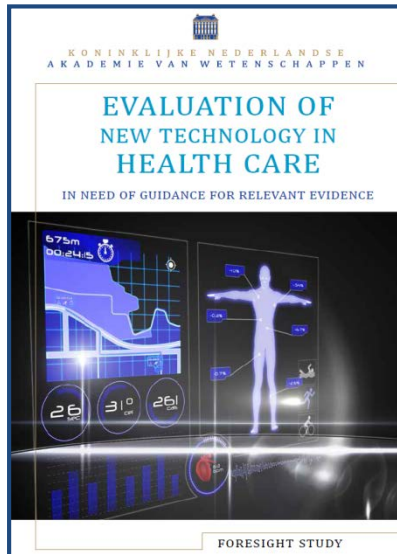
USA 2015



MEDICAL DEVICE INNOVATION CONSORTIUM

Patient-Centered Benefit/Risk Report

“More patient centric benefit-risk assessment needed”



Netherlands 2014



KNAW

“Scientific approaches to assess benefits, risks and performances of medical devices”



Haemodialysis any time, any place, anyhow

Even in countries currently unable to offer haemodialysis

Any time



- > More frequent and/or longer dialysis for better health
- > Can be used without help (remote connectivity)
- > Enabling dialysis at night, giving you back your life during the day

Any place



- > Small and portable
- > Easily taken on trips (air cabin hand luggage)
- > Restoring your autonomy and mobility

Any circumstances



- > Small volume fluid bag < 6L
- > 115V / 230V ac, 60/50 Hz
- > External DC battery pack option
- > Enables haemodialysis in areas with poor infrastructure
- > Disaster response & field hospitals
- > Flying doctors interested

Major step towards portable artificial kidney

Debiotech, AWAK and Neokidney Development sign partnership to bring compact home haemodialysis machine to first patients by 2017



Lausanne, May 23rd 2014 – Today three international innovators join forces to develop and deliver to patients the world's first portable artificial kidney. Debiotech of Switzerland, AWAK of Singapore and Neokidney Development, an initiative of the Dutch Kidney Foundation, have signed a joint venture agreement to complete a functional model in 2015. Clinical trials are planned for 2017. The portable artificial kidney will enable the frequent and longer home haemodialysis that significantly improves and extends patients' lives.

We're on track

NEOKIDNEY 

A Dutch Kidney Foundation initiative,

Endorsed by the



International Federation of Kidney Foundations

improving kidney health worldwide



Combine 2 PD technologies



- Multimedia
"Swiss pocket knife"

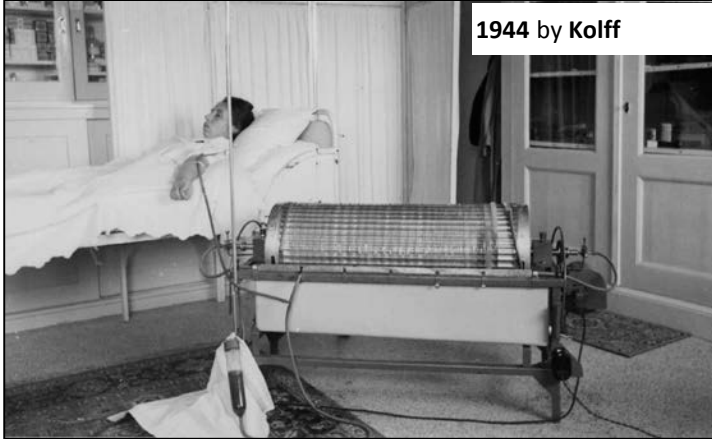


2017: HD

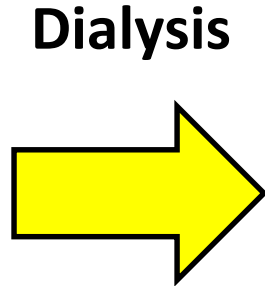


- No plumbing
- No rewiring
- AC/DC

Near Future of Home HD



1944 by Kolff



2017 planned
first human use



Daily Blood Pressure



Blood Pressure

Weight

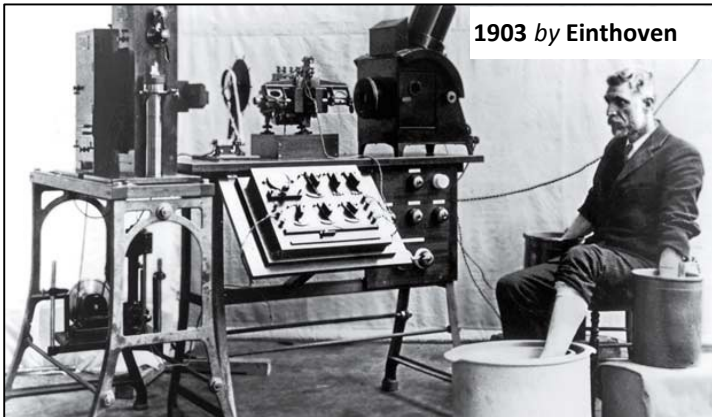


Video & Wireless connected
Carry-on air travel size
No home alterations needed

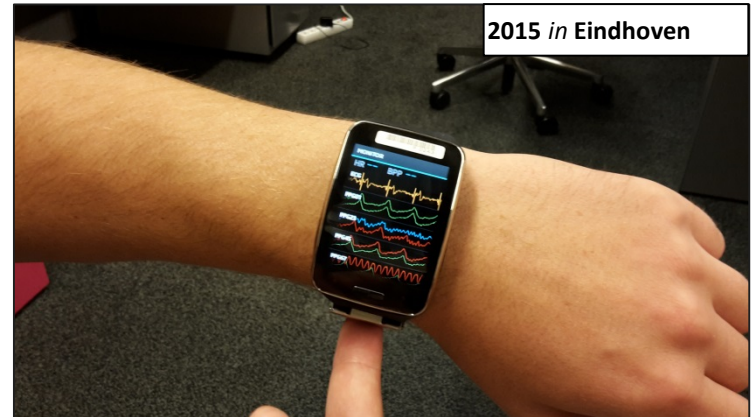


Wherever you go:

- Blood Pressure trend
- ECG



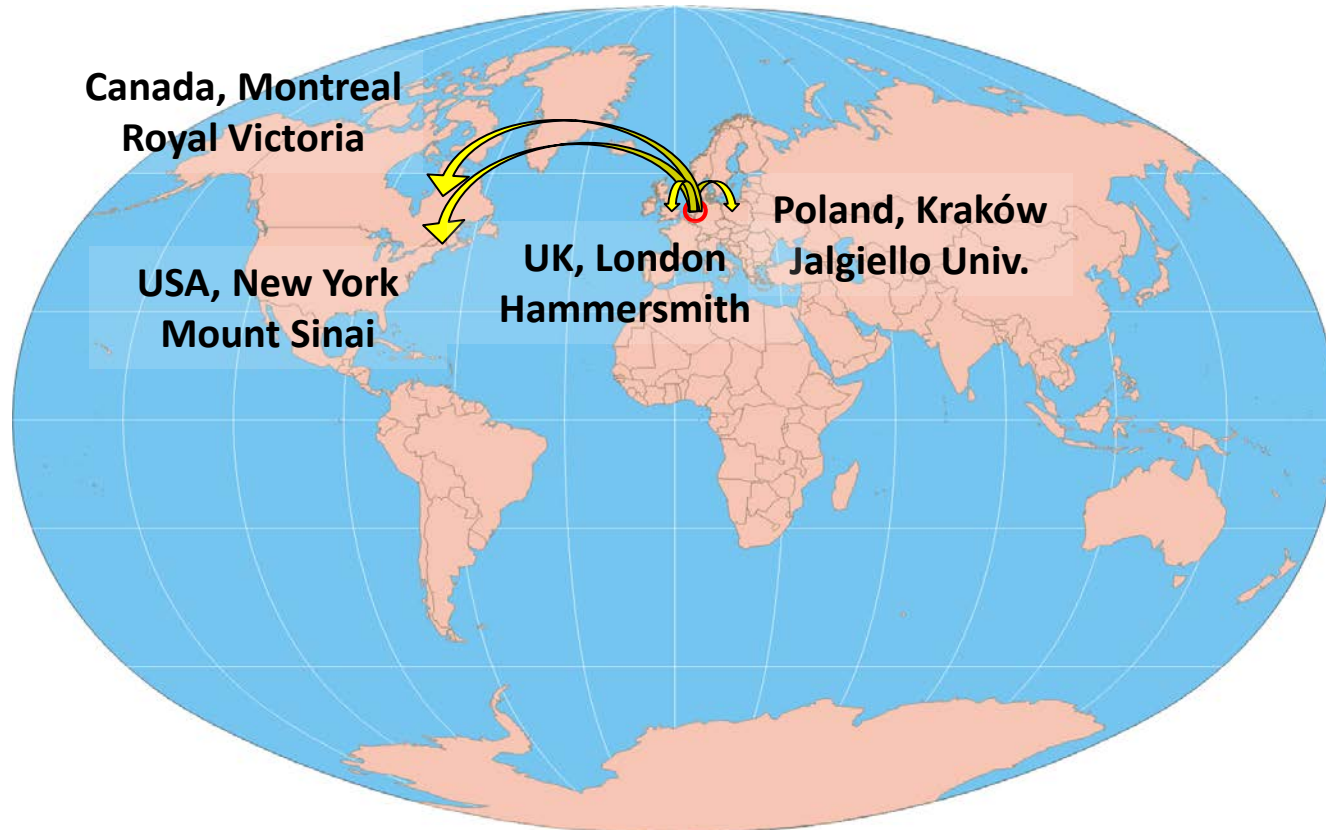
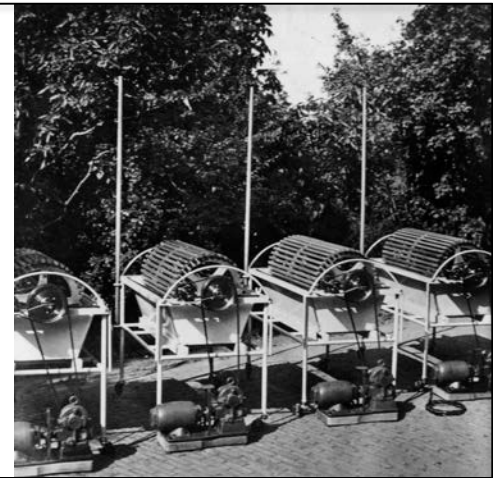
1903 by Einthoven



2015 in Eindhoven

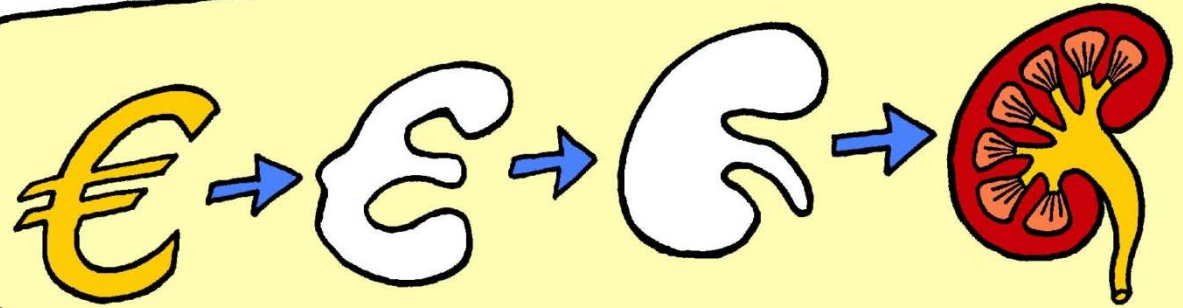
Dr. Kolff believed in co-operation:

- **He didn't patent his invention**
- **But built 4 extra machines and sent them out across the world (at his own expenses...)**



World-wide problem: Co-operation = Key

Amazing:
Scientific research
revealed that it also
works with \$, £, ¥
and many more
currencies !!!



**Dutch Kidney Patient
Association**

www.nvn.nl

info@nvn.nl

NEOKIDNEY

A Dutch Kidney Foundation initiative

www.neokidney.nl

info@neokidney.nl



**Dutch Kidney
Foundation**

www.nierstichting.nl

info@nierstichting.nl