

# Dietary Management, Lifestyle Adaptations, Psychological & Social Support

## Patient Working Group

Brenda de Coninck

Flavia Galletti

Jared Grantham, MD

Nicole Harr

Tess Harris (co-lead), presenter

Eiko Hodouchi

Uwe Korst

Corrine Lagrafeuil

Luisa Sternfeld Pavia

Kaori Yamane Winston

Dwight Odland (co-lead)



# Disclosure of Interests

No relevant disclosures

KDIGO



# Physical, Biological & Psycho-social Burden



# Lifestyle Modifications

## Addressing patient confusion:

- What changes should I make to my lifestyle now? How can I help myself?
- I have to drink 'water' but why and how much? Does the amount vary by gender, size? How do I know if drinking water works?
- If I live in Africa, how can I afford or even get enough water to drink? What about water quality variability? Or fluoride content?
- I've read about kidney patient diets on the web:
  - Do I have to give up protein and bananas?
  - I've read that caffeine is 'bad' – should I stop drinking tea and coffee?
- Should I take – or avoid – vitamin supplements?
- I'm asymptomatic:
  - How do I know if these lifestyle changes will have any effect over my lifetime?
  - How can I stay motivated every day?
- What if I stray from my 'strict PKD diet'? Am I making things worse?



# Psychological Help

## Living with a life-threatening incurable disease:

- Diagnosed and asymptomatic:
  - Fear of the future: progression variability/will I die young?
  - What about my career and family hopes?
  - Where can I find help to relieve stress and anxiety?
- Slow deterioration of quality of life:
  - Lack of energy affecting work, home and social life
  - Dealing with periods of debilitating illness and pain
  - Dialysis/transplantation while still relatively young
- Massive kidneys and liver size:
  - Clothing challenges, body image, feeling bloated/fat
  - Being thought pregnant or obese
  - Impact on relationships and sexuality



# Hobbies and Sports Advice

## No more bungee-jumping:

- Will my favourite hobby make things worse?
- I've been told to avoid 'contact sports' – what are these?
- What could I do that might improve my physical condition?



# PLD

## As frightening as PKD for some patients:

- Will the same PKD lifestyle modifications help with PLD?
- Impact on women in particular:
  - Contraception advice
  - Post-menopausal advice



# Finding Factual Unbiased Support

## Healthcare Professionals (HCPs):

- Variability owing to ignorance, geography etc
- No Guidelines

## Internet and family:

- Accuracy/consistency
- Frightening

## Support groups:

- Developed world only
- Cultural nuances
- Under-funded





# Integrated Management of ADPKD

## Co-ordinated/inter-disciplinary care:

- PKD is systemic: it's more than a 'kidney' disease.
- Patients need clear guidance about management, eg:
  - Frequency of monitoring by HCPs
  - Self-management (weight, BP etc)
- What can be learned/applied from management of other complex chronic conditions?
- Specialised Centres of Excellence?
  - Co-designed with patients
  - Benefits to patients and payers
  - A human right?



# ADPKD PROMS

## If presumed to improve outcomes:

- What should be included?
- Global working group?
- What are next steps?

