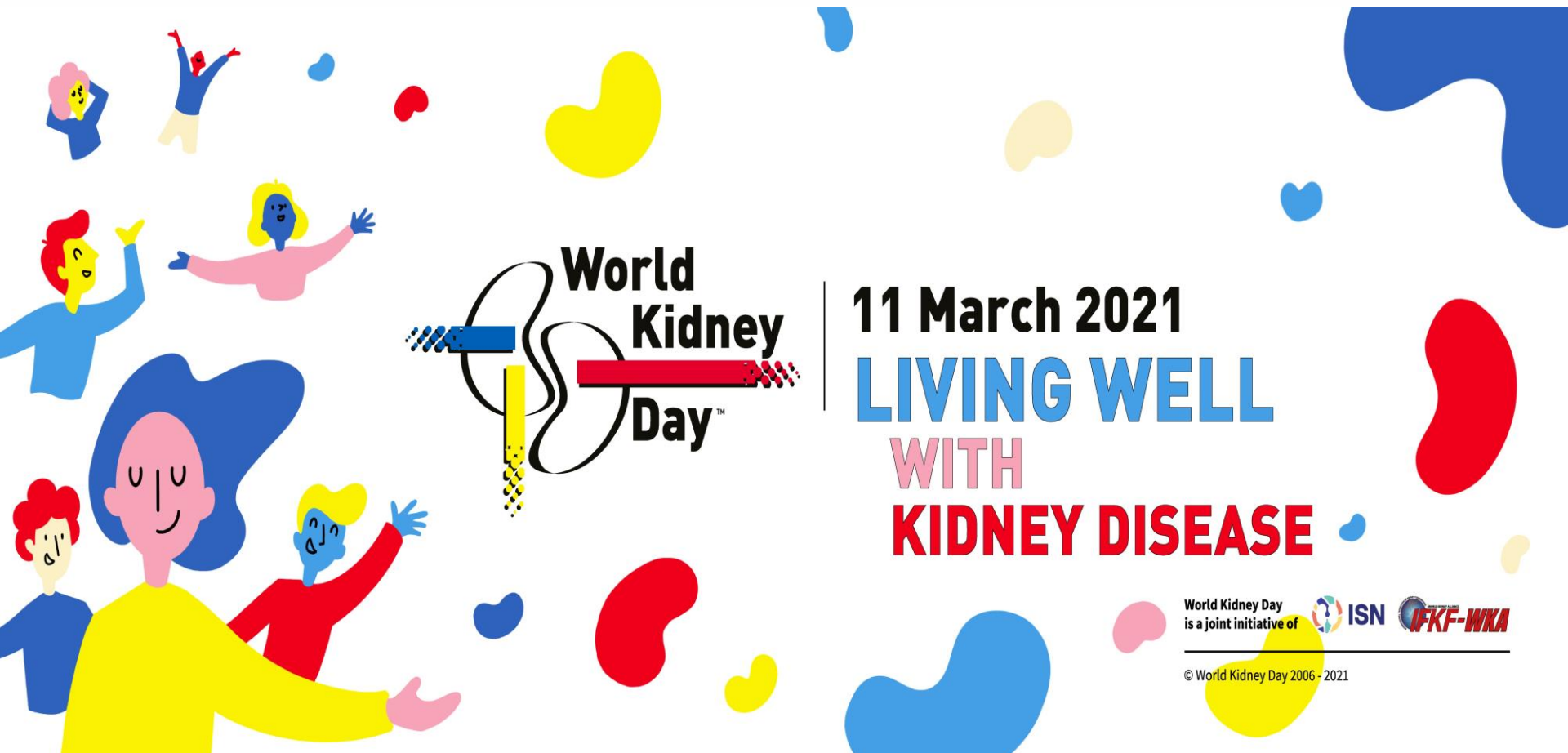


# Parents Who Have Children with CKD



# Living Well With Kidney Disease

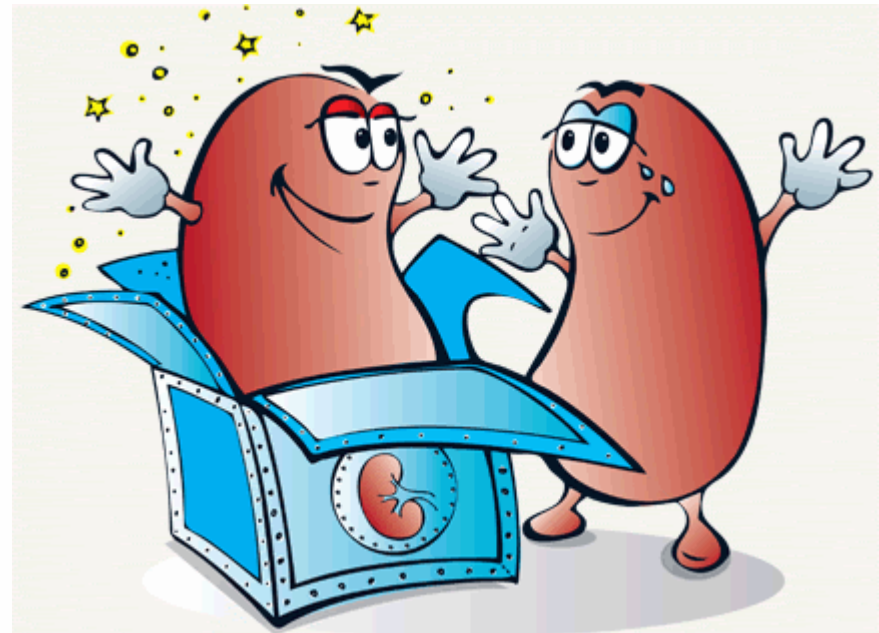
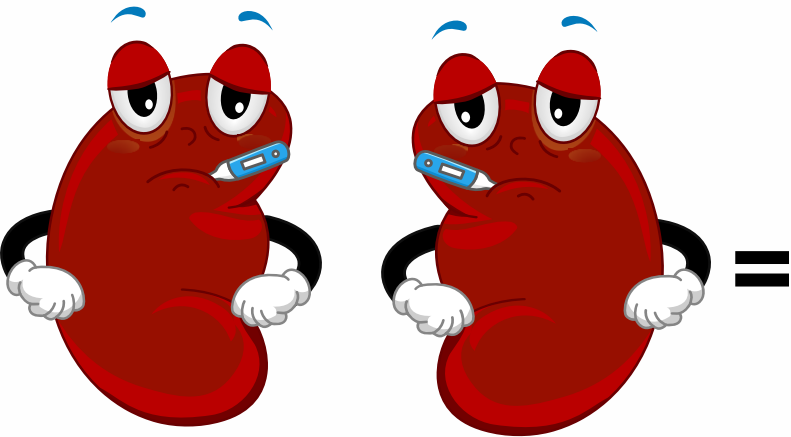


**11 March 2021**  
**LIVING WELL**  
**WITH**  
**KIDNEY DISEASE**

World Kidney Day is a joint initiative of  ISN  IFKF-WKA

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# When both kidneys stop working for good



# NKF Tips for Parents

- **Learn about the disease and its treatments**
  - Learn as much about your child's disease and its treatment as you possibly can.
  - Encourage your child to ask questions not only of you but of doctors, nurses and other health professionals.
  - Don't try to explain more than your child can understand, but don't lie and don't apologize for any treatments or procedures that have to be followed.
  - Help your child understand that the doctors, nurses, social workers, dietitians, laboratory personnel and everyone else is on his or her side.



# NKF Tips for Parents

- **Actively participate in your child's care.**
  - Develop a spirit of mutual respect and cooperation with health professionals.
  - Write out all the details of your child's medical history, including dates.
  - Try to be with your child as much as possible during treatments and any hospitalization that might be necessary.
  - If your child is not talking yet, it's a good idea to tape a note to his or her hospital bed or crib with helpful information for the staff, such as favorite foods, special toys or blankets, preferred time and method of taking medicines.



# NKF Tips for Parents

- **Help your child take control of the illness.**
  - Try to maintain a normal daily routine, even during hospitalization.
  - Help your child understand about doctor's offices, hospitals, dialysis units and laboratories and how they are used.
  - Be creative in finding ways for your child to participate in his or her own care.



# NKF Tips for Parents

- **Help your child to understand and accept diet restrictions.**

- Even a child as young as 2 or 3 can understand about "diet" if it is explained simply.
- Have your child make a list of favorite foods and take him or her with you when you talk to the dietitian to see if these foods can be incorporated into the diet plan.
- Whatever you do, don't ever use bribes or force your child to eat



# NKF Tips for Parents

- **Don't let medicine time ruin your day.**
  - A matter-of-fact attitude is your best weapon in getting your child to take medication.
  - A good trick with babies and small children is to use syringes minus the needles to dispense the medication.
  - Your child has no choice about whether or not to take prescribed medication, but you can offer a choice of when and where.
  - And once the choice is made, make a schedule and stick to it.
  - Sometimes medication must be given with meals, but don't give it at the table where your child eats.
  - Another weapon you have at medicine time is plain, ordinary water.





# NKF Tips for Parents

- **Share your experience with others.**
  - Don't let yourself become isolated.
  - Don't hesitate to ask relatives and friends for help.
  - Sharing your experience will help you find ways to grow with it.



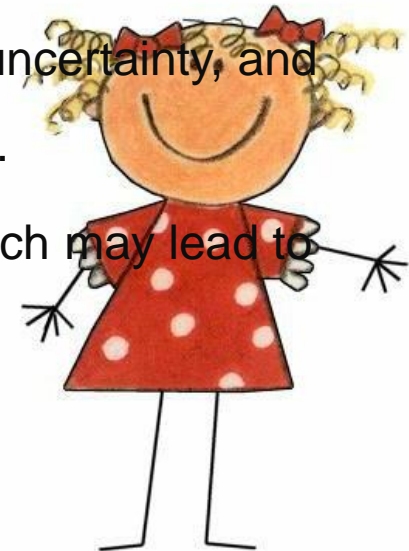
# Experiences of Parents Who Have Children With CKD

systematic review, Pediatrics  
2008

- In addition to “normal” parental roles, being a parent of a child with chronic kidney disease demands:
  - A high-level health care provider,
  - Problem solving,
  - Information seeking,
  - Financial and practical skills at a time

when the capacity to cope is threatened by physical tiredness, uncertainty, and disruption to peer support within and outside the family structure.

- Parents of children with CKD need multidisciplinary care, which may lead to improved outcomes for their children.



# The support needs of parents having a child with a chronic kidney disease: a focus group study

- It is important that healthcare professionals should not only attend to the abilities of parents concerning their child's disease management, but also focus on the parents' abilities in balancing their responsibilities as a caregiver with their own personal life.

– Geense et al. *Child Helth Care Dev*, 2017



# Child and parental perspectives on communication and decision-making in pediatric chronic kidney disease: a focus group study

- Parents value partnership with clinicians and consider long-term and quality of life implications of their child's illness.
- Children with CKD want more involvement in treatment decision-making but are limited by vulnerability, fear, and uncertainty.
- There is a need to support the child to better enable them to become partners in decision-making and prepare them for adulthood.
- Collaborative and informed decision-making that addresses the priorities and concerns of both children and parents is needed.
  - **Gutman et al. Am J Kidney Dis, 2018**



# Parental health literacy and progression of CKD in children

Ricardo et al, *Pediatric Nephrology* (2018)

- The authors assessed the parental health literacy of 367 children
- Median CKD participant age was 9.5 years, 63% were male, and 59% non-Hispanic white.
- Median eGFR at baseline was 63 ml/min/1.73 m<sup>2</sup>
- Median urine protein-to-creatinine ratio was 0.22.
- In this cohort of children with CKD, higher parental health literacy was associated with a nearly 30% longer time to the composite CKD progression outcome.



# Sources of distress experienced by parents of children with CKD on Dialysis: A qualitative systematic review

Ong et al. *Journal of Pediatric Nursing*, 2021

- A total of 23,129 title and abstracts were reviewed; 161 full texts were reviewed. Thirteen papers, with the experiences of 183 parents, met the inclusion criteria. Most included studies were conducted in Western countries, which may limit the applicability of this review to other countries.
- Results: Five themes emerged: disease-related distress, personal struggles, family structure, lack of resources and unrealistic social expectations.



# How do parents deal with their children's CKD?

A qualitative study for identifying factors related to parent's adaptation, Khorsandi et al. BMC Nephrology 2020

- A qualitative study with a content analysis approach.
- Seventeen parents of children with CKD were selected by using purposive sampling.
- Semi-structured, in-depth, face-to-face interviews to collect data
- increasing parent access to the required information, supporting them financially and emotionally, and helping them identify support resources can facilitate their adaptation to their child's chronic illness. Also, identifying and eliminating adaptation barriers can help parents deal better with their child's chronic disease.



