



PRACTICAL INTEGRATED PATIENT SUPPORT (PIPS)

KDIGO

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Disclosure of Interests

No disclosures to report

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Centers of Excellence – only a partial answer

Our Belief: *Because of the general lack of knowledge by health care providers in treating rare kidney diseases, there is a great need for Centers of Excellence*

What they solve:

- Availability of trustworthy, up to date (and most importantly - continuously up to date) treatment and care
- One stop shop for all needs related to disease progression

How many are needed? What level of care could be considered a COE?

How to facilitate access?

What they don't solve:

- Excellent health care for the other 95%
- Continuity of lifestyle and medication adherence between visits

Post-visit materials needed?

- Wikipedia vs Facebook examples



Family Planning and The Future

When will PGD become common? When should it?

Multiple Issues involved with possible use of PGD to eliminate genetic kidney diseases

- Ethical, Moral, Legal, Financial, Religious

The future with government-controlled health care and ROI considerations

- Conditions for lifetime coverage of so-called expensive diseases?
- Where will lines be drawn? Where should they?



Psychological Impact, Financial Decisions

Inherited disease impacts on patients and families

- Patients generally look normal / healthy
- Transition from health to ESRD is emotionally difficult
- Depression is common

Lifespan / quality of life realization may lead to decisions with long term impacts

- Spend vs save
- Unhealthy lifestyle choices
- Decisions related to reproduction
- Short-term focused career choices and impacts to the family security
- Obsession with health and finances, etc – a vicious circle
- Suicide ideation - children and adults

How to reduce these negative impacts on adults and children?



Also

Effective Patient Organizations

How to maximize the energy of their volunteers for maximum impact:

- Health Policy
- Spending levels
- Research focus
- Partnering effectively with stakeholders

Would international partnerships or even mergers increase effectiveness?

What are the potential downsides of ceding local control?



Other PIPS topics to explore

Adherence – Why so difficult?

- Lifestyle
- Medications

ESRD Emotional and Social Impact on Children

Transitioning Care from Childhood to Adulthood

Tailor a PROM for Rare Kidney Diseases?

Breaking Barriers to Drug Access

Maximizing Caregiver Impact



Summary

Questions? Comments?

We welcome your input

We look forward to collaborating with the other groups
when patient perspectives are considered

