June 9-10, 2008 Meeting Between
The *Association Italiana Rene Policistico*
and
The *PKD Foundation*
To Review/Discuss International Partnering Opportunities
Hello Dan…I am pleased to inform you that AIRP has held its annual meeting yesterday. I was confirmed as President, and the affiliation to PKD Foundation International was voted unanimously. Therefore, I shall be mailing to you tomorrow the signed memorandum of understanding between our organizations.

Looking forward to our mutual cooperation, I remain

Sincerely

Marco
Dear Professor Soria

“I am very pleased to hear the good news coming from the AIRP Annual meeting...

- that you’ve been confirmed as President of the AIRP
- and that affiliation to the PKD Foundation International was voted unanimously.

I look forward to meeting with you, Alessandra and other AIRP leaders— in early June, and partnering together toward our ultimate goal...a treatment and/or cure for PKD!!

Dan Larson”
Dear Dan...

“I would kindly ask you to give me suggestions for initiatives you would like to discuss with the AIRP, I will ask Marco Soria to do the same and will create an outline of the meeting.

Very much looking forward to this!

Alessandra”
I will prepare a PowerPoint wherewith we can
• review the basic tenets of the PKD Foundation’s
  Internationalization initiative
• review how the AIRP ...as a PKD Foundation
  ‘partner,’ can best
  – fulfill its goals
  – maximize its strengths
  – and build for the future
• consider basics components of an AIRP ‘business
  plan’
• and allow ample time for Q & A.
The above e-mail exchange represents what we hope to achieve via International Partnerships ‘between the PKD Foundation and PKD patient organizations…around the world…

• **Strategy:** The PKD Foundation seeks to serve as the *catalyst* for the establishment of *interdependent, yet autonomous*…International PKD partners.

I’m hopeful our discussions today…will help the AIRP, the PKD Foundation…and the leaders of both, achieve the above!!
“Success” – and “achievement”…

…what does that mean…to

• The Association Italiana Rene Policistico?

• You as its leader?
“Your progress…”

• Can you give me an update?

• What are your main challenges?
“Goals, aspirations...needs”

What goals, aspirations and needs do you and the Association Italiana Rene Policistico have for the -

• Next 1-2 years?

• Next 3-5 years?
Review of PKD Foundation’s Int’l Initiative

**Purpose:** Global Mission/Vision Fulfillment

**Mission:** “Promote programs of research, advocacy, education, support and awareness to discover treatments and a cure for Polycystic Kidney Disease and improve the lives of all it affects.”

**Vision:** That **no one** (worldwide) suffers the full affects of PKD
International Partnering Opportunities

Philosophy: Simply stated, “12.5 million people depend on us!”

Strategy: The PKD Foundation seeks to serve as the catalyst for the establishment of
• interdependent, yet
• Autonomous...

…International PKD partners.
International Partnering Opportunities

**Tactic:** Enable/empower PKD partners to
- pursue mission & vision fulfillment
- by focusing on *your* unique capabilities and strengths – within four basic areas of emphasis:

1. Patient education/support
2. Resource development
3. Research advancement
4. Public awareness.
PKDF ‘Partners’ are now organized in...

PKD Foundation International

- PKD Foundation Canada
- PKD Foundation Japan
- PKD Foundation France
- PKD Foundation Australia
- PKD Foundation Germany
- PKD Foundation USA
- PKD Foundation Korea
- PKD Foundation China
- PKD Foundation Switzerland
- PKD Foundation Italy
With ‘partnerships’ to be implemented (later this year) in...

- The Netherlands &
- India
Partnership Benefits

• Guidance
• Training
• and Resourcing…to partnering PKD organization

– To facilitate the registration/recognition as an official Non-Governmental Organization (NGO).
Partnership Benefits (cont)

• The synergy of many international components, working together…
  – toward a common mission
  – to produce greater results than individual organizations working separately…
  – Collectively causing positive impact on many, MANY more PKD families, worldwide
Partnership Benefits (cont)

• Each organization will:
  – be empowered to increase their local/national presence as part of global alliance.
  – access current and consistently accurate PKD educational, training and support resources to expand the impact of each
  – have a website/presence developed and implemented for them in the official language of their country
Partnership Benefits (cont)

(Each organization will:)

– receive support, consultation and resourcing assistance (i.e. marketing, public awareness, fundraising, etc.)

– have a ‘seat at a table of equals’
  • Participating in annual strategic planning sessions…crucial to sustaining true partnerships.
Each organization will:

- be provided information from world-renown scientists involved in PKD research and clinical practice... about the best in
  - scientifically meritorious research
  - effective clinical practice
  - strategic scientific meetings
  - Important collaborations
  - and patient/professional education opportunities
partnership Benefits (cont)

(Each organization will:)

• be empowered to do “more-with-less”

• be able to connect their constituents with
  – international patient conferences
  – And the latest development in clinical trials, potential therapies and symptom care.
partnership Benefits (cont)

(Each organization will:)

• develop and share
  – A common Brand identification (logo, look, feel, etc.)
  – to increase synergy and impact by an expanding critical mass of organizations and PKD constituents
Current Administrative Leadership Team

Dan Larson – President
Collaboration/Leveraging

Mark Stone
Business/Leadership Development

Jody Gloor
Program Management
Important Partnership Basics

• International Organizations’ accountability:
  – From programmatic and financial standpoint – Local Board
  – funding scientifically meritorious research – PKD Foundation’s Scientific Advisory Committee

• Each PKD Foundation ‘partner’ will serve as a resource development partner yet operate autonomously in the daily functions of managing the local organization.

• PKD Foundation ‘partners’ will access financial, medical, and volunteer resources in-region – for region
Initiatives/Resources Required

• Development & Implementation of an International Patient Conference – Spring, 2009
  (underwritten through grants, sponsorships, fees)

• Acquisition of capacity-building funds through Grants, Sponsorships, and Donor-Designated Funding (projected investment: $250K - $500K over three years).
PKD Foundation Research Funding

The Foundation supports only peer reviewed and scientifically meritorious research; our O U.S. funding (41 total projects) reflect Int’l objectivity

- France
- Germany
- Italy
- Japan
- Netherlands
- Hungary

- Switzerland
- United Kingdom
  - England
  - Wales
- Canada
  - Ontario
  - Quebec
  - Ontario.
As we see it, the *Association Italiana Rene Policistico*. –

• …as an existing organization – has a basic framework on which to build
  – Leadership positions and individuals are identified
  – An AIRP Association Scientific Committee…is in place
  – An effective website has been developed
  – Some promotional activities have occurred
  – And Q & A sessions were held with doctors and PKD patients
Possible ‘next steps’ of growth for the Association Italiana Rene Policistico. – may be

- Patient and physician education
- Enlistment of additional members (via public awareness)
- Exploring fundraising opportunities
- Strengthening credibility with existing Italian ‘kidney organizations and developing strategic partnerships
- Consideration of developing a “business plan structure” (i.e. like the following…only as a starting point)
PKD Foundation
International Business Plan Template

I. EXECUTIVE SUMMARY

II. MISSION & VISION: Why the PKD Foundation International exists

III. DESCRIPTION & HISTORY: PKD Foundation International
IV. PURPOSE: International PKD Foundations/Associations

• Value-Added Partnership

• International Nonprofit Community and Philanthropic Receptivity Analysis
V. PROGRAM PLAN: Providing Quality Patient Services, Education, & Support

• Patient Support

• Patient Education
VI. MARKETING PLAN: Establishing a Presence within the Region

• Target Market

• Public Awareness Strategy
PKD Foundation
International Business Plan Template

VII. DEVELOPMENT PLAN: From Fundraising to Donor Cultivation

• Special Events
• Development of Volunteer Network
• Individual Donor Cultivation/Development
• Government grants
PKD Foundation
International Business Plan Template

VIII. OPERATIONAL PLAN: Leadership and Effective Support Functions

• Management Team
• Administrative/Operational Necessities
IX. FINANCIAL PLAN: From Start-up to Financial Stalwart

- Projected Financial Statements
  - Projected Revenue Streams – Years 1-3
  - Projected Expenditures – Years 1-3

- Financial Assumptions

X. EXIT STRATEGY: For International Partners that, unfortunately…do not make it
Your…

• Questions?

• Challenges?

• Needs?
“12.5 million people with PKD – depend on me!”