

PVRI India Task Force Report 2021

Plans to establish a legal, not-for-profit subsidiary in India.

Report by Prashant Bobhate & Qadar Pasha

The challenge and background to the current scenario in India...

India is a huge country, with a population of 1,392,700,000 and ready to overtake China as the most populous country in the world by 2027. The country is extremely diverse and democratic and consists of: 28 states; 8 union territories; 121 spoken languages and; 6 main religions practiced.

The prevalence of PH in India...

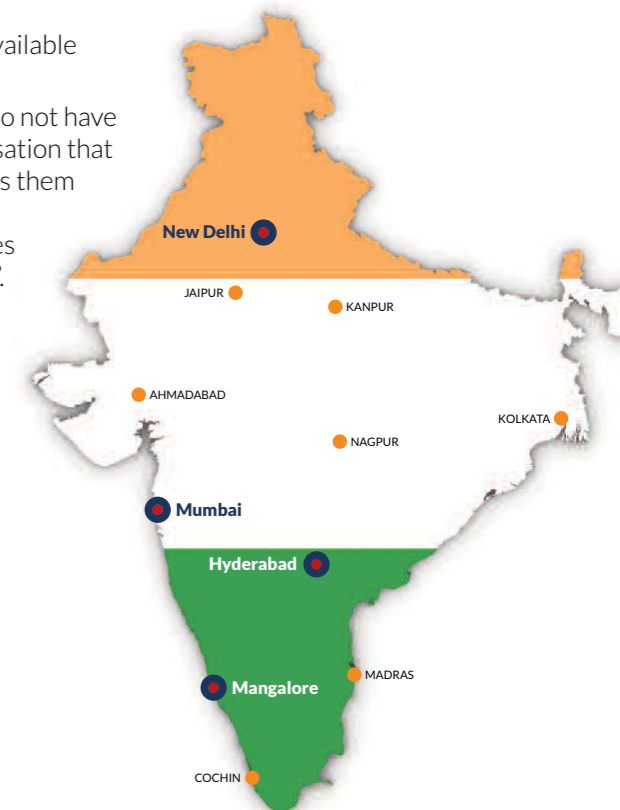
- PH is considered a rare disease. However, current patient estimates suggest over 100,000 patients, many undiagnosed without medical care.
- The Pro-Kerala registry in 2018 published 2,003 patients - the second largest registry in the world. Data was collected from Kerala (one of the smaller states) with high levels of literacy and an excellent health infrastructure.
- At 3 centres in Mumbai, Hyderabad and Kochi there are more than 1,500 patients currently diagnosed to have PH.
- Over 200,000 babies born each year with congenital heart disease.
- We can easily assume that PH presents a huge medical problem and unmet need.



Pulmonary hypertension in India...

- PH is neglected due to the vast discrepancy in the doctor to population ratio, currently 1:1456 (compared to the UK: 1:330).
- At present there are only 4 dedicated PH clinics in the entire country.
- Lack of awareness of the disease, sketchy referral patterns and lack of standard guidelines for evaluation management of PH, leaves the overall care provided to the patients at the individual discretion of the treating physician.
- The Pro-Kerala registry also demonstrated that only one out of two patients with PAH is receiving PH specific therapies.

- Limited available drugs.
- Patients do not have an organisation that represents them and that undertakes 'advocacy'.



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The opportunity...

- Ready-made network of Task Force leaders with 197 members.
- Building on previously run successful activities:
 - Bi-annual high altitude Leh Symposium.
 - Annual PVRI conferences for 3 years in a row with at least 2 international faculty.
 - 2 Paediatric PAH conferences in 2 years preceding the COVID-19 pandemic.
 - At least one PVRI conference in each region over the last 2 years with national faculty.
 - 'Living with PH' a unique webinar for the patients, by the patients - facilitated by PVRI India Task Force and attended by 1,700 participants from all over the world.
 - PVRI quiz competition for postgraduates. Attended by more than 600 students from all over the country.
 - Set-up an informal patient support group.
 - Set-up 8 Task Forces of experts who have started work to write guidelines for managing PH in India.
- Ready-made accredited PH online diploma course, developed by PVRI UK, can be adapted for the Indian medical community.
- Huge fundraising potential due to no formal patient body.

The proposal...

Set-up a legal subsidiary in India of the PVRI

Proposed directors of PVRI India:

- **Mumbai**
Dr Prashant Bobhate PAEDIATRIC CARDIOLOGIST
- **New Delhi**
Dr Qadar Pasha GENETICS
- **Hyderabad**
Dr Bhahavatula Kutumba Srinivasa Sastry ADULT CARDIOLOGIST
- **Mangalore**
Dr Abraham Babu CARDIAC REHAB
- **Mumbai**
Dr Sujit Rajan PULMOLOGIST
- **Hyderabad**
Dr Vishwesharan PULMOLOGIST
- **Shalaka Parab** PATIENT WITH PH WHO IS ACTIVELY MANAGING THE CURRENT PATIENT SELF HELP GROUP, ENDORSED BY THE PHA, USA.
- **Professor Ghazwan Butrous** FOUNDER OF PVRI UK



Our plans...

- Set-up a separate legal entity in India and register as a not-for-profit charity.
- Mission and vision aligned to PVRI UK.
- Activities to mirror PVRI UK fit-for-purpose for India & South East Asia region.
- Indian directors to cover the geographical area of the country.
- One patient representative on the Board of PVRI India who is aligned with PHA USA, the largest PH patient organisation in the world.
- One director from the UK: Professor Ghazwan Butrous, founder of PVRI UK.
- Separate Indian bank account.
- Annual audits in India and the UK.
- Transparent book keeping and financial audit trails using SAGE accounting software.

The legal structure...

Working with the UK India Business Council which is approved by the UK Government & Foreign Ministry UK India Business Council to provide support throughout the setting up process ensuring:

- Legal compliances.
- Registered address.
- Book keeping, accountancy and audit services.
- Setting up of bank account and monitoring all financial transactions.
- Communication with UK head office.
- Approval by UK accountants and auditors.
- Ensuring all government regulatory compliances are adhered to.
- Register for not-for-profit/charitable status ensuring tax exemption.
- Compliance of all potential fund-raising activities.
- Provide local administration and management support.

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India's unique characteristics...

- No PH referral network.
- Only 4 established PH centres of excellence.
- No legal or recognised framework of PH patient bodies.
- No formal PH focused fund-raising.
- Approximate PH patient estimate over 100,000, many undiagnosed without medical care.
- Over 200,000 babies born each year with congenital heart disease.
- Very proactive India Task Force running established activities.
- Yoga in PH research study funded by The Dinosaur Trust 2021-2023, endorsed by WHF.
- Goodwill and pro bono work from engaged patient body.
- Medical links to UK and USA doctors originating in India.
- Population: 1.4 billion people (compared to the USA: 330 million).
- Sophisticated economy.
- Tax incentives for companies to give to charities. Over 600,000 high net-worth individuals (earning over USD 1 million).

The proposed activities over the next 3 years...

Increasing awareness of PH in health care practitioners

- Annual PVRI India conference with at least 2 international faculty (covering all specialities).
- At least one CME activity yearly, in all the tier one cities of the country (we have 8 tier one cities in India).
- Helping to set-up one PH centre in each of these cities.
- Masterclass for PG students to increase the awareness of the disease in the formative years.
- Creating an app which would act as a virtual bridge between the patients and doctors to help manage patients better.
- PVRI Annual World Congress on PVD to be held in India within 3 years of launch.

Increasing awareness in general public and helping PH patients

- Establishing a formal patient support group under the PVRI India umbrella to add credibility for fundraising activities.
- PH day activities including: podcasts, FM radio activities and newspaper articles and press releases.
- Informative website for patients presented in regional languages.

The investment required...

- Secure start-up funds from PVRI UK via a grant from the Cardiovascular Research and Medical Fund (CMREF) in the USA.
- Confirm sponsorship from Indian national pharma companies which is essential.
- Plan proactive fundraising activities via PH patient network.
- Identify high profile patrons to engage business community and provide advocacy.

- Undertake a fundraising campaign from PVRI UK to attract support from its worldwide network of PH physicians.
- Initiate advocacy in collaboration with PHA USA, the target PH patient organisation in the world.

Expanding the PVRI global mission...

- Validates PVRI's global reach.
- Emphasises unmet PH need in developing world providing advocacy with WHO, NCDA, WHF, etc...
- Increases partner opportunities.
- Encourages exchange programmes.
- Provides shadowing and mentoring opportunities.
- Facilitates sponsorship of Fellowships.

The aim is
500
Indian members
within 3 years

