

How to find reliable & high quality donors

DATRI Blood Stem Cell Donors Registry

Presented by: Raghu Rajagopal, Co-Founder & CEO

On: 12th May 2017, Cologne

DATRI's inception







The right elements to building a successful registry in India

- ✓ HLA typing experts with entrepreneurial spirit
- ✓ Founders of Histogenetics
- ✓ An Indian entrepreneur with international experience in the field

The best decision was for the three of us to come together to start the registry to address the lack of Indian donors to help the Indian patients worldwide.







An ideal donor!

-  **18-50 years** of age
-  Complete **understanding** of the process
-  Asks the **right questions**
-  Registers with **no peer pressure**
-  Can take **independent decisions**
-  Believes in being able to **counsel the influencers**

Indian Landscape



-  Population **1.3 billion**
-  **29 States** | **7 Union territories**
-  **22** officially recognised **languages**
-  More than **2000 ethnic** groups





DATRI - Indian Registry



- 🌸 2,10,000+ donors Vs Population of 1.3 billion
- 🌸 DATRI spread across 23 states | 65 Employees
- 🌸 15 Apheresis (Collection) centres
- 🌸 31 National and 28 International
Transplant centres
- 🌸 255 donations facilitated till date
- 🌸 First in the country to set up processes in place






Donor recruitment challenges in India



-  **Low Awareness**
-  **Baseless Religious Taboos and Myths**
-  **Lack of Trust**
-  **Diverse and Large country**

Donor retention challenges in India



-  Change in contact details
-  Family interference
-  Lack of govt. support and guidelines
-  No Health Insurance for Donors
-  Other challenges (Deficiencies – Vit D, B12, under weight)

Challenges in Donor Counselling in India



Better counselling


- ❁ In the beginning, all our counselling efforts used to be in person.
- ❁ Now, 85% of all our counselling happens on phone.
- ❁ This is because we have successful case studies to present to donors.
- ❁ Increase in ACs and TCs across the country has created more comfort and trust on DATRI.


Donations – Disease profile

Disease Group	Patients
Acute Myelogenous Leukemia	67
Thalassemia	52
Acute Lymphoblastic Leukemia	45
Severe Aplastic Anaemia	22
Myelodysplastic Disorders	13
Inherited Immune System Disorder	11
Others	9
Inherited Erythrocyte Abnormality	7
Chronic Myelogenous Leukemia	7
Non-Hodgkin's Lymphoma	6
Other Leukemia	4
Plasma Cell Disorder	3
Inherited Metabolic Disorder	3
Acute Myeloid Leukemia	3
Histiocytic Disorders	3
Total	255

Donors – Recruitment %

Organisation Type	No of Registrations	%
Educational Institutions	87,881	42.79%
Corporates	61,263	29.83%
Residential Dwellings	24,729	12.04%
Others	8,620	4.20%
Religious Institutions	8,440	4.11%
Hospitals	5,562	2.71%
Events	3,010	1.47%
NGO	1,940	0.94%
Government Organisation	1,469	0.72%
Clubs	1,461	0.71%
Hotels	980	0.48%
Total	2,05,355	100%

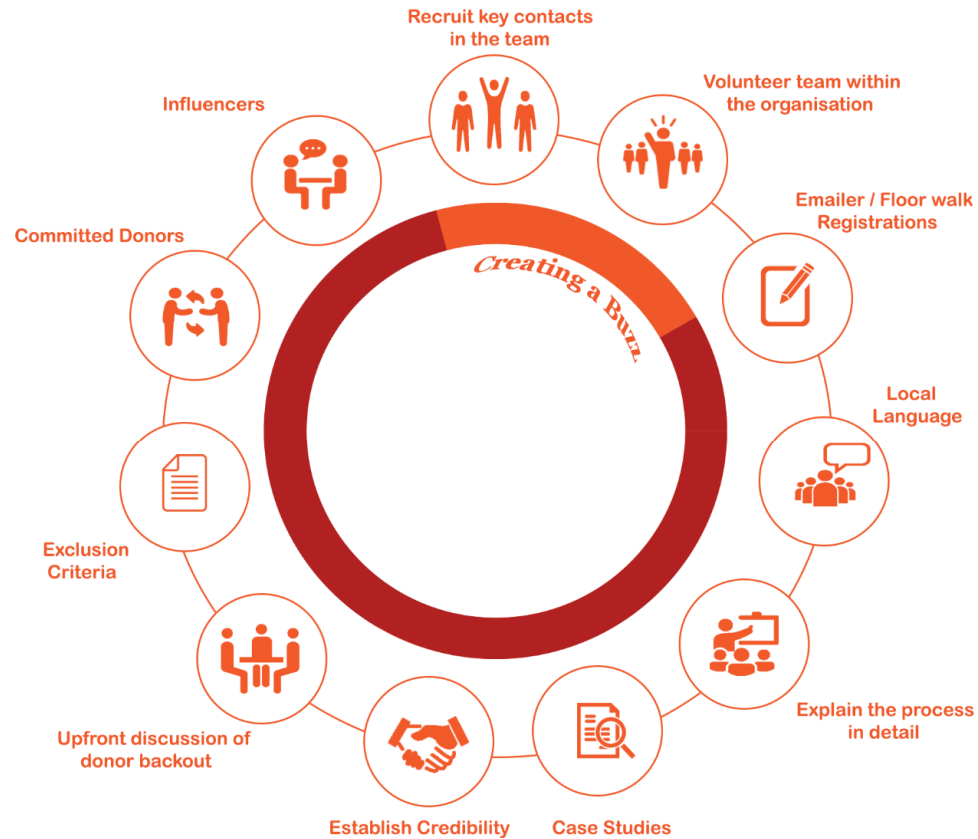
 Awareness and donor recruitment in **Colleges, Corporates and Community Centres**

 **Patient related drives** are also organised, with extra care given to patient confidentiality and to register only high quality reliable donors who will donate for others too.

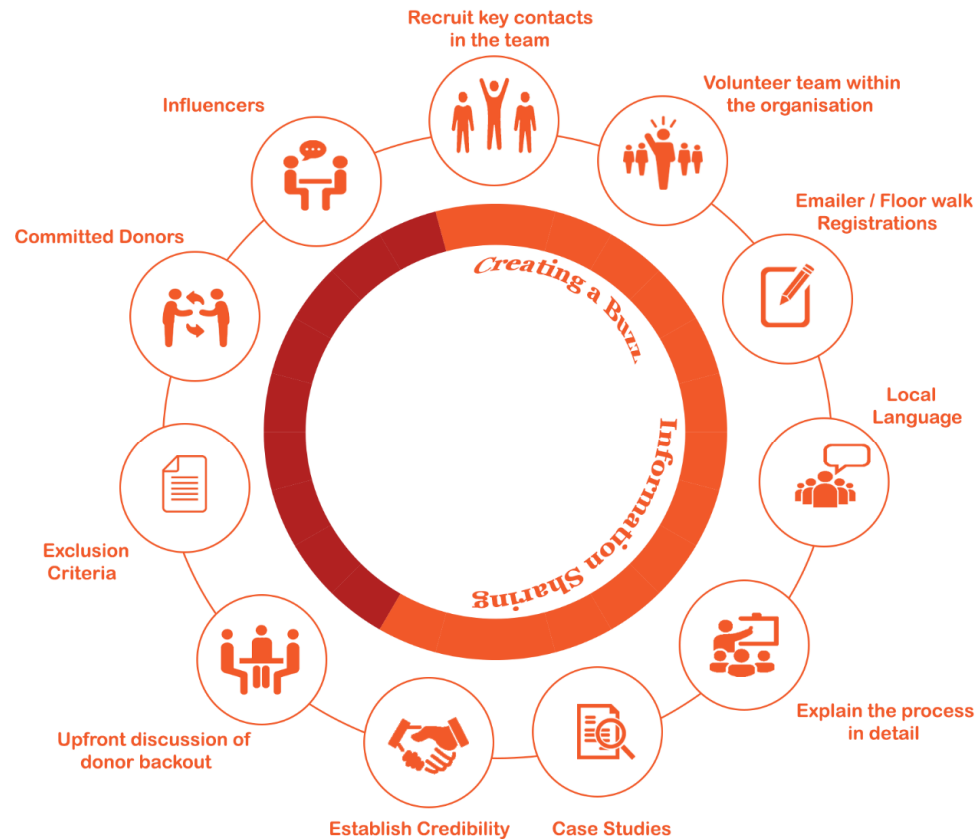
Why donors back out?

- ❁ **Family** permission (parents, spouse, siblings, fiancé, inlaws etc.)
- ❁ Registered due to **peer pressure** / compulsion
- ❁ Hesitant to **spare time** for the donation
- ❁ **Questions** and **doubts** about the process
- ❁ Do not understand the seriousness that he/she is **the ONLY**
hope for a patient

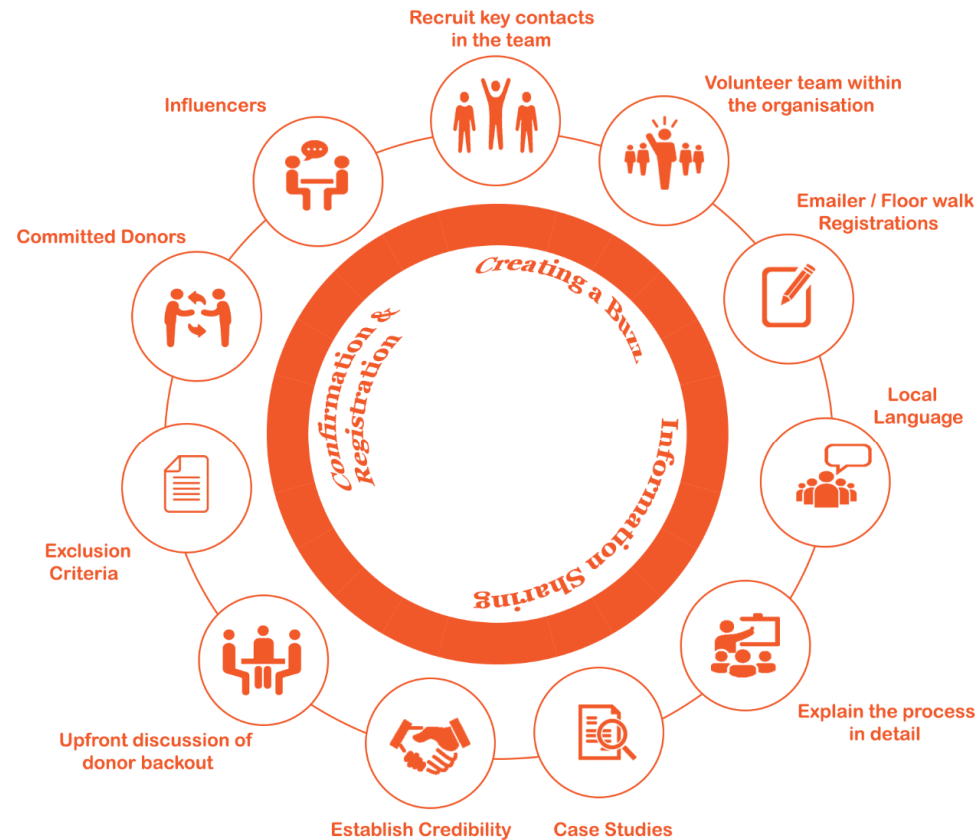
The process – awareness & recruitment



The process – awareness & recruitment



The process – awareness & recruitment



How DATRI has overcome challenges?

- ❁ Register/recruit **only committed** donors
- ❁ Information and education material in **different languages**
- ❁ Exclude **ineligible donors** at the stage of recruitment
- ❁ Diverse and Competent **Team to counsel** potential donor and family
- ❁ Ensure to have the best Standards/Quality – process, infrastructure, trained professionals
- ❁ Other – reach through Doctors (GPs), Use Donors who have donated, Donor-Recipient Meet, events, welcome kit, retention team, newsletter, birthday mails etc

DATRI's Retention team



A well trained donor retention team that ensures prompt follow up with donors

 Call a sample of donors (15%) from every drive.

 Welcome Kit

 Mail after each donation

 Birthday wishes

Consent Form



DONOR INFORMED CONSENT FORM

D20

BARCODE :

The following disclosure confirms my informed consent to be a registered DONOR in DATRI and DATRI's agreement and commitment to me.

1. Any information that is obtained in connection with registering as a donor at DATRI and that can be identified with me, will remain confidential and will not be disclosed to anyone outside the authorized personnel of DATRI's team
2. I agree to have my sample collected, typed, stored and listed on DATRI's registry to determine if I am a possible match for any patient and also for any other registry purposes.
3. I would like to have my sample HLA typed at any well-equipped and experienced lab in the world.
4. I will be given access to my information any time on request.
5. I have read the awareness material and /or have been explained the process of donation.
6. I am aware that my HLA data may be used for research on population genetics and transplant outcome.
 - a. Population genetics is essential for any registry to assess the diversity of the population it is serving, to make sure that is proportionally represented in the registry. This will help to provide more available donors for the patients who are in need for blood stem cell transplant.
 - b. Transplant outcome may be influenced by the variation in HLA and non-HLA immune response genes. Match and mismatch status for those genes and its influence on transplant outcome is

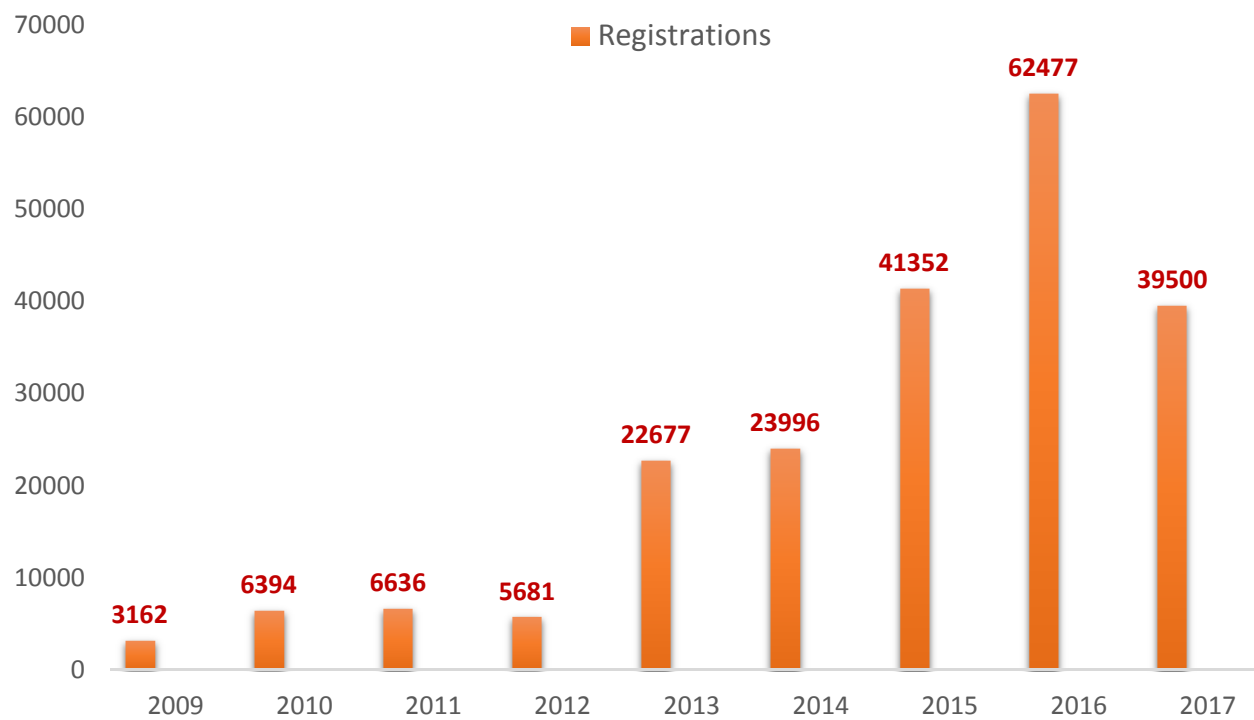


DECLARATION OF UNDERSTANDING

D20

S.No	Description	Response
1	I have read and/or been explained the process of Peripheral Blood Stem Cell (PBSC) and Bone Marrow donation and I understand the processes.	YES / NO
2	I intend to share details of my registration as a volunteer blood stem cell donor as well as the donation processes with my parents/spouse/siblings	YES / NO
3	I am registering as a voluntary blood stem cell donor because I want on my own accord and have not been pressurized by anyone to register.	YES / NO
4	If I am found to be a match for any patient in need, I will be contacted by DATRI. If I agree to donate I understand that: <ol style="list-style-type: none"> a. I may have to give 5 ml of blood for verifying the match b. I am required to go through pre-screening tests as per DATRI protocol at a DATRI approved hospital called The Apheresis Center(AC) c. I can donate my blood stem cells, only if the AC doctor certifies me as fit to donate d. Once I go through the prescreening tests and am found fit to donate, the donation dates will be mutually agreed and fixed 	YES / NO

DATRI's growth



Year	Donations
2009	0
2010	0
2011	3
2012	16
2013	26
2014	34
2015	59
2016	84
2017	33

THANK YOU!

For any queries please contact,

Email: raghu@datriworld.org

Website: www.datri.org

Phone: +91 44 2254 1283

Headoffice: Ticel Bio Park Phase II, Module no. 1207 & 1208, 12th Floor, Taramani-CSIR Road, Chennai -600113

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