



DATRI CONNECT

1

MANAGEMENT DESK

Dear Doctors,

As we step into another year dedicated to our unwavering mission, we would like to underscore the significance of the doctor newsletter in fostering collaboration and driving the success of DATRI's vision to provide hope to individuals grappling with blood cancer and blood disorders.

The Doctor Newsletter serves as a crucial communication channel that not only recognizes your pivotal role but also keeps you informed and engaged in the ongoing efforts of DATRI.

In the newsletter, you will find articles penned by our passionate team members, shedding light on the challenges we face, the triumphs we celebrate, and the advancements that propel our mission forward. These articles serve as a window into the heart of DATRI, showcasing the collective commitment and the streamlined processes that aim to make a positive impact on the lives we touch.

We encourage you to take a moment to peruse the insightful articles within the newsletter. Your feedback and suggestions are highly valued, as they contribute to the continuous improvement of our practices and approaches. Your expertise is not only acknowledged but celebrated within the pages of the newsletter.

The doctor newsletter is a testament to the collaborative spirit that defines our partnership. Your role is integral to the success of DATRI, and we eagerly anticipate your continued support as we navigate this journey together.

Warm regards,



Claudia Rutt
Chief Financial Office



Sumati Misra
Head – Medical Affairs



2

PRELIMINARY WORK-UP FORM: STREAMLINING THE PATH TO LIFESAVING TRANSPLANTS

Jayashree Shankar

Head – Search, Match & Transplant Services

DATRI has recently introduced a pre-workup form which has been shared with all doctors. This form aims to assist the organization in prioritizing urgent cases and managing donor expectations regarding possible collection dates. The inputs on the form enables DATRI to address any initial challenges proactively and ensure a positive donor experience.



The Preliminary Workup Form plays a crucial role in the transplantation process, specifically when a Transplant Center Physician submits a Verification Typing (VT) request for a potential donor identified through the DATRI search report. This form is instrumental in gauging the urgency of the transplant, assessing the financial readiness of the patient, establishing a timeline for the workup, and addressing special patient considerations, such as concessions, eligibility for government funding, or classification under the Below Poverty Line (BPL) category

Importance of the Preliminary Workup Form:

- 1. Understanding Transplant Urgency:** By obtaining this form at the initial stage, the transplant team gains insights into the urgency of the transplant, allowing them to prioritize cases effectively.
- 2. Financial Preparedness Assessment:** The form helps assess the patient's financial readiness, facilitating the planning and coordination of financial resources for the transplant process.
- 3. Workup Timeline:** Establishing a clear timeline for the workup ensures efficient coordination between the donor and the transplant center, avoiding unnecessary delays.
- 4. Patient-Specific Considerations:** Identifying whether the patient requires concessions or falls under special categories aids in tailoring the approach to their unique needs.

Reasons for Utilizing the Preliminary Workup Form: The completion of this form serves several crucial purposes:

- 1. Prioritizing Donor Identification:** Allows for prioritized identification and counseling of potential donors based on physician-provided remarks.
- 2. Customized Scheduling:** Provides a structured schedule for the donor, enabling them to plan their availability accordingly.

Challenges Faced in Case of Workup Delays:

In instances where there is a delay in the workup process after confirming donor availability, several challenges may arise, necessitating careful consideration:

- 1. Voluntary Nature of Donation:** Blood stem cell donation being a voluntary process, delays may lead to donors reconsidering their decision, emphasizing the importance of prompt action.
- 2. Donor Availability Issues:** Personal and professional commitments may affect donor availability, potentially causing unanticipated challenges in scheduling.
- 3. External Influences on Donors:** External factors, such as influencers (friends, relatives, etc.), can impact a donor's decision, highlighting the need for maintaining a positive and supportive environment.
- 4. Match for Another Patient:** A donor may be found as a match for another patient, requiring efficient communication and coordination to avoid conflicts and address time constraints.
- 5. Influence on Other Potential Donors:** Delays in one donor's workup may influence the decisions of other potential donors, particularly in scenarios involving college or corporate drives.

Given the life-saving nature of the transplant process and the unique challenges associated with donor coordination, timely completion and careful consideration of the Preliminary Workup Form are critical to ensuring the success of transplantation and maintaining the trust and hope of both patients and donors.

3

ENSURING DONOR CONFIDENCE: IMPORTANCE OF PATIENT STATUS UPDATES POST-TRANSPLANT

Dhivyaa Ranganathan

Senior Associate - Transplant Centre Management

At the donors registry, we initiate communication with transplant center doctors to provide crucial status updates about patients who have benefited from the generosity of our donors. This information holds paramount importance as donors often inquire about the well-being of the recipients they have supported. The prompt dissemination of these updates not only satisfies the curiosity of donors but also reinforces their faith in our organization, contributing to the recruitment of more donors.



The impact extends beyond mere updates; our past donors, who have experienced the fulfillment of helping others, become valuable advocates for the cause. One-year post-transplant updates serve as a key tool in strengthening our bond with donors, encouraging them to share their positive experiences with potential contributors who may be hesitant.

Conversely, misinformation or lack of communication could impact the donor's opinion about the organization and its work. Some donors leverage their social media presence to influence potential contributors, affecting donor recruitment efforts. This underscores the critical need for accurate and transparent communication to prevent misunderstandings that might hinder a patient's chances of finding a suitable match.

Thus timely and transparent communication from transplant center physicians is vital, both before and after Bone Marrow Transplant (BMT). Prior to the transplant, keeping potential donors informed during the workup process is crucial for managing expectations and addressing potential challenges. Failing to maintain open communication may result in donor hesitation or withdrawal, impacting not only the current patient but also influencing the decisions of other potential donors.

4

THE VITAL ROLE OF PATIENT UPDATES IN RECRUITMENT

Dhivyaa Ranganathan

Senior Associate - Transplant Centre Management

In the realm of unrelated donor pools, discovering a potential match for a patient brings a ray of hope to their family. The journey from finding a match to processing collection and transfusion varies for each patient, with some facing urgent needs due to serious diseases, while others can afford to wait. Managing these diverse timelines becomes crucial, highlighting the importance of keeping donors informed about tentative schedules.

Prompt communication from transplant center physicians plays a pivotal role in updating donation managers and coordinators about potential changes in timelines. Donors are often counseled for urgent stem cell donation, and any delays arising from financial constraints, patient health complications or the availability of a related donor must be communicated promptly to DATRI by the transplant center's medical team.

A communication gap between DATRI and transplant centers can lead to donors backing out and erode their trust in the registry. A disillusioned donor might influence the decisions of other potential donors. Instances have been observed where delays in the workup process caused donors to change their decision and withdraw support.

Many donors who backed-out report being counseled with false information regarding the urgency of the collection process. This not only results in the loss of a potential donor but also hinders their willingness to counsel others. The ripple effect extends to the overall chance of finding a compatible donor for the patient.

While most requests from transplant centers stress urgency due to the unpredictable nature of blood cancers and disorders, maintaining open lines of communication and providing prompt updates can prevent donors from backing out. Establishing a realistic timeline not only instills confidence in donors but also fosters a sense of involvement in the process.

Effective communication and transparency in patient status updates are essential elements in donor retention and recruitment. By navigating this journey with diligence, we can strengthen the bond between donors and registries, ensuring a higher probability of successful matches and, ultimately, improved outcomes for patients in need.



5

DATRI'S COMMITMENT TO BRIDGING HOPE

Jayanthi Sampath, Associate Manager – Transplant Center Management

"The power of NGOs lies in their ability to turn compassion into action, creating a ripple effect that transforms lives and builds a better world for all." - Melinda Gates

DATRI, with its primary vision of providing a chance to every patient in need, extends its support to individuals worldwide battling blood cancer. Currently boasting a registry of over five lakh donors, we prioritize the well-being of both donors and patients, ensuring the delivery of cost-effective services.



The initial donor registration involves an HLA typing cost of INR 1800/-, a significantly discounted rate from Histogenetics for DATRI. As the donor matching process progresses, DATRI incurs additional costs such as Infectious Disease Markers, Imaging tests, donor travel expenses, accommodation, GCSF injections, recommended supplement medicines, and hospital collection costs, among others. Administrative expenditures associated with operating as an NGO, compounded by the absence of government funding, necessitate reliance on CSR funding or corporate funding and the generosity of individuals.

While a donor registering today may not immediately find an opportunity to donate, some matches may extend even a decade into the past. The counseling process, crucial for assuring donor safety, may require in-person sessions, prompting our team to travel to meet donors. Travel costs are covered by DATRI, and for long-distance donors, both travel and accommodation are provided before donation. In cases where donors request support for their family members' travel and accommodation, DATRI ensures the necessary arrangements, including flight or cab bookings, depending on the location.

Behind the scenes, a dedicated team at DATRI, including transplant center coordinators, donation managers, and the Head of Medical Affairs, collaborates with critical yet less visible roles like donor recruitment coordinators, retention teams, and data entry associates. Support teams in Accounts, Finance, Quality, Human Resources, Marketing, Information Technology, and Management Information System contribute to the seamless functioning of the organization, assisted by Apheresis centers and various laboratories.

Expenses incurred in the run-up to a successful donation

Conducting awareness drives & registering blood stem cell donors



**Counselling - the donor & his / her influencers.
Meeting them, if required**



Medical check - up - exhaustive medical check-up to ensure donor & patient safety. Meeting a doctor & answering all queries



Mobilization - GCSF for 5 days & monitoring of mobilization & prospective cell count.

Travel & stay of donor and DATRI coordinator

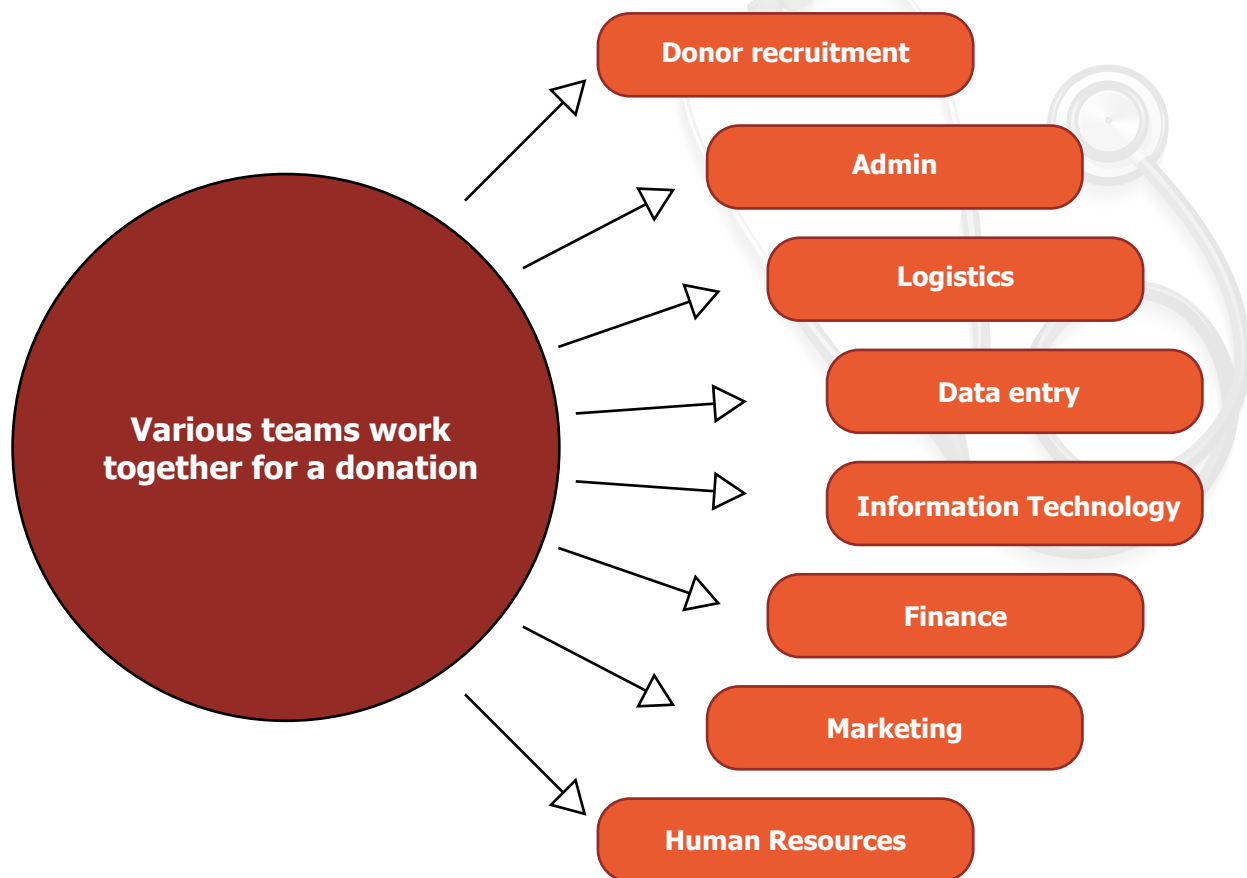


Collection - at a reputed hospital, under the care of tenured doctors & nursing team



Product Transport - transporting the product via human courier to the location where the patient resides within 24-48 hours





Keeping costs low as a non-profit, DATRI remains conscientious of every rupee spent. Recognizing the financial challenges faced by patients, we strive to deliver quality services within their means. Although some patients seek reductions in charges, DATRI, bound by regulatory constraints as a registry, carefully evaluates each case and provides concessions based on established standards, considering the patient's financial situation and Transplant Center requests. While the organization endeavors to accommodate requests, limitations exist in extending concessions to every patient.

In conclusion, DATRI emerges as a powerful force in the realm of NGOs, epitomizing Melinda Gates' profound insight: "The power of NGOs lies in their ability to turn compassion into action, creating a ripple effect that transforms lives and builds a better world for all." With an unwavering commitment to saving lives and offering hope to those battling blood cancer, DATRI's compassionate endeavors create a ripple effect that extends far beyond the immediate impact. Through a robust registry of dedicated donors, cost-effective services, and compassionate support teams, DATRI navigates the complex landscape of matching donors to patients. Despite financial challenges, the organization remains steadfast in its mission, ensuring that every rupee spent is a step closer to providing a new lease of life to those in need. DATRI's transformative actions exemplify the potential of NGOs to effect positive change. Through its dedication, DATRI not only gives patients a new lease of life but also contributes to building a better world, one rooted in compassion, resilience, and the promise of a brighter future.

6

ENHANCED SCREENING PROTOCOLS: RESPONDING TO ANOMALOUS INFECTIOUS DISEASE MARKER RESULT

Jayashree Shankar,
Head – Search, Match & Transplant Services

In the course of evaluating unrelated donors, our commitment to safety extends beyond routine infectious disease marker assessments. Following the completion of these evaluations, we engage in a thorough review process with our Medical Director, Dr Jose Easow, who, in turn, meticulously examines the donor's comprehensive test report file. Recommendations, including additional tests or approval for the continuation of the process, are provided as part of this collaborative assessment.

While the primary responsibility for donor clearance lies with the collection center, we strictly adhere to a four-eye principle, ensuring our medical director provides an additional layer of scrutiny. The table below highlights some recommended additional tests by the DATRI Medical Director.

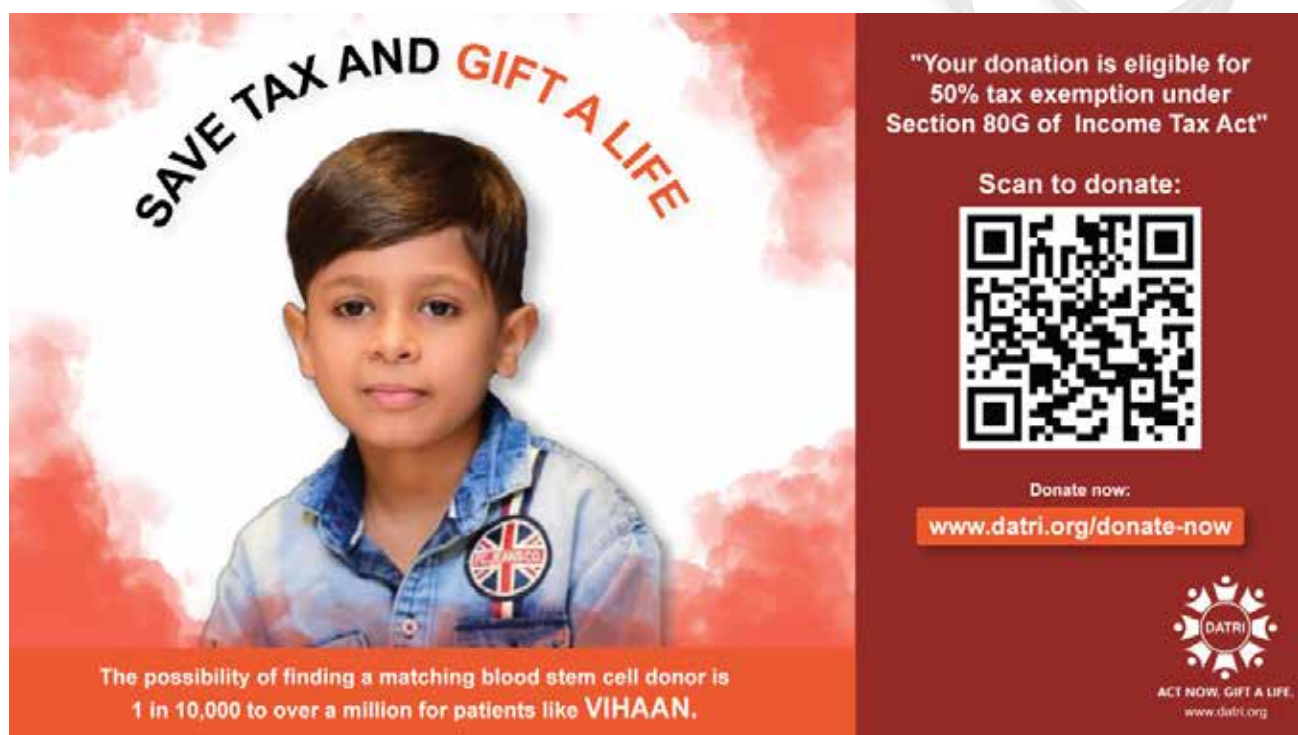
No	Scenarios	Additional Tests Recommended by DATRI Medical Director
1	Reactive HIV / HTLV	Repeat check in another lab for discrepancy. If positive, donor to be deferred from workup.
2	Reactive VDRL/RPR	TPHA to be performed in addition to repeat VDRL/RPR. If positive, donor to be deferred from workup.
3	Reactive HBC Total	Repeat test along with HbE Antigen, Anti HBsAg, and HBV Viral Load.
4	High APTT, Low Fibrinogen, and Ferritin	Factor 8, 9, and 12 to be done along with repeat PT and APTT.
5	High RBC and Low Ferritin	Repeat RBC along with Alpha Beta Globulin Gene Mutation Analysis, Heinz Body Prep, and Cytogenetic studies (if required).
6	High WBC	Repeat WBC along with BCR ABL FISH, PCR, MPN Reflux Panel Test.
7	High Total Protein	Serum Protein Electrophoresis (SPEP).
8	High AST and ALT	Repeat test followed by Gastroenterologist Clearance.
9	Abnormal ECG & ECHO	Cardiologist Clearance is required.
10	Splenomegaly	If Spleen Size is more than 13 cm, donor to be deferred from workup.
11	Hepatomegaly, Liver Enlargement	Hepatologist Clearance is required, and PET Scan in case-to-case assessment.
12	Cyst in USG scan	Additional tests to rule out the cyst and respective specialist clearance required.

This strategic and comprehensive screening approach underscores our dedication to ensuring the utmost safety of both the donors and the recipients in the transplantation process.

7

YOUR DONATION CAN HELP SAVE TAX AND GIFT A LIFE!


Ten-year-old Vihaan suffers from Thalassemia Major a blood disorder. Vihaan was diagnosed with Thalassemia Major when he was five months old and from that time he has been on blood transfusions regularly. His only hope is to find a matching blood stem cell donor. Your contribution can help us to find a potential donor and gift a life to Vihaan.



SAVE TAX AND GIFT A LIFE


"Your donation is eligible for 50% tax exemption under Section 80G of Income Tax Act"

Scan to donate:



Donate now:
www.datri.org/donate-now

The possibility of finding a matching blood stem cell donor is 1 in 10,000 to over a million for patients like **VIHAAN**.


ACT NOW, GIFT A LIFE.
www.datri.org