

A Guide to Establishing a Collaborative Rare Donor Programme

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Section I. - Valuable Initial Information to collect

When establishing a collaborative rare donor programme, there is information that is helpful to start the programme, especially in collaboration with other facilities.

- A. Communicating with laboratories studying patient's samples
 - 1. Identify other laboratories performing immunohaematology investigations beyond a single panel in your area of the country if desire is to establish a regional project.
 - 2. Or, in your country if medically well-organized and centrally managed this could also be countrywide in a country with a small population or small geographic area.
 - 3. It will be useful to identify individuals with high potential for active communication.
 - 4. A survey of laboratories providing transfusion services may be useful for collecting information on interested facilities.
- B. Survey what antibodies are being identified and how many are not identified
 - 1. Retrospective data, if able to be obtained, will be more efficient in terms of elapsed time but may not be available.
 - 2. Proactive data collection may be more informative if a survey tool is developed that captures information in a standard way. This could include patient ABO, other antigen typing results, all alloantibodies identified including antibodies to common antigens, diagnosis, ethnicity of patient, if blood was obtained locally, through siblings, or needed to be imported, chronic or episodic transfusion need, and outcome of patient case or hospitalization.
 - 3. Collect information on policies regarding referral to a local Immunohematology Reference Laboratory or to the International Blood Group Reference Laboratory if an antibody is not identified.
- C. Identify medical and technical leadership personnel with immunohaematology experience
 - 1. Create a list of individuals who could be responsible communicators for the project.
 - 2. Obtain commitment for communication.
 - 3. Determine if both technical and medical specialty professionals are needed in this communication listing.
 - 4. Identify the availability of these individuals and preferred communication choices.
- D. Identify where antigen typing of donor units is being performed
 - 1. This could include private or public laboratories, referral centres, national laboratories.
 - 2. This may require staffing commitment to antigen typing.
 - 3. This may enable antigen negative units to be made available more quickly.
 - 4. Alternatively, the center may choose to perform when a patient's need arises.
 - a. This may conserve resources.
 - b. This may delay access to antigen negative blood.
- E. Track requests for antigen negative units
 - 1. Tracking antigen negative requests will enable centres to predict need for antigen negative blood of "common" antigen types.

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2. Identification of the highest requested types will enable a prediction of what antigen types to test for.
3. Rare blood needs may include a need for “common” antigen negative types be known.
4. Track data on units requested as useful by the centre.

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Section II - Structure determination

When establishing a collaborative rare donor programme, determining the structure of the programme can be helpful in identifying challenges and solutions.

- A. Define the interested parties
 1. Local interested personnel and facilities
 - a. The contact list created in Section 1 could be contacted to determine interest in being a part of planning the structure for a rare donor programme.
 - b. Additional requirement for personnel could be defined by the organizing person or centre or by using interested staff on the contact list.
 - c. It is important that the individuals assisting with structure development include those with responsibility for provision of blood as well as testing staff in the department or facility providing the blood products.
 2. Regional network potential
 - a. If the contact list is a local list, consider whether a potential exists for a regional service.
 - i. If yes, use Section 1 as a basis for structure development regionally.
 - ii. If not, determine if there is interest or need for a contact list for times when rare blood is needed and is not available locally.
 3. National programme development
 - a. Generally, consider, based on the geography and size of the country, whether a national rare donor programme is desired and possible as the programme starts.
 - b. Also pertinent is whether there is a national basis for routine blood provision.
 - i. If yes, examine with responsible staff, the potential to develop a national rare donor programme in the initial phase.
 - ii. If no, proceed with the plans for local or regional programme
 - iii. Inform national health leaders or authorities as needed.
 4. International participation
 - a. Communicate with the Lead of the International Rare Donor Panel (IRDP).
 - b. Contact with the ISBT Working Party on Rare Donors.
 - c. Consider participating as a mentee in the ISBT Mentorship Programme.
 - d. Determine how to submit donors to the IRDP.
- B. Determine the parameters of the project
 1. Rare Donor Registry – developing a listing of rare donors
 2. Include Registry for Patients requiring rare blood.
 3. Determine the breadth of the project.
 - a. Initial considerations for the project may include:
 - i. Consider if uniform donor consent is desired or required.
 - ii. Plan for testing donors for desired antigens (budget and staffing).
 - iii. Determining number of donors and antigens to test.
 - iv. Requirements for staffing resources to test per plan.
 - v. Determine how donors will be qualified to register them.
 - vi. Methods used, serologic or molecular

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- vii. Number of times to test to register donor
 - viii. Plan for contacting siblings of patients requiring rare blood
 - ix. Plan for recruiting ethnicities with higher potential for rare blood types
 - x. Determine and agree on what parameters are in scope and what are out of scope.
- C. Determine the involvement of donor centres and hospital facilities in the planning and communication activities, including time commitments.
 - 1. Determine support and resource needs.
 - a. Determine if shipping logistic policies are required or if they are in existence for routine blood shipments.
 - b. Determine if fees for rare blood supply are needed.
 - c. Explore grant funding opportunities.
- D. Determine the approval process for the project
- E. Rare Donor Programme – developing a collaborative activity that includes a registry of rare donors, recruitment activities, responding to needs for rare donor products.
 - 1. Determine the breadth of the project.
 - a. Initial considerations for the project may include the Registry components listed in section B 3 a above.
 - b. Plan for tracking rare donors, communications with them about rare status and recruitment.
 - c. Plan for contacting siblings of rare donors.
 - d. Plan for recruiting ethnicities with higher potential for rare blood types.
 - e. Testing criteria
 - f. Aliquot and/or unit freezing ability or future plan
 - g. Plan for training donor collection staff about rare donors
 - h. Consider recognition program.
 - 2. Determine the involvement of donor centres and hospital facilities in the planning and communication activities.
 - 3. Determine support and resource needs.
 - 4. Determine action steps and responsible staff.
 - a. Develop documents and gain approval for action steps within purview of department.
 - b. Develop recommendations or refer to existing documents where indicated.
 - c. Make a list of responsible staff in documents by department and position as appropriate.
 - d. Determine the approval process for the project timeline to complete action steps.

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Section III - Participating centres

When establishing a collaborative rare donor programme, identifying the roles and responsibilities of the participating centres can be invaluable in setting up the programme.

- A. Blood centre, hospital, local laboratory participation levels
 - 1. Blood centre/hospital participation
 - a. Consider if the blood centre/hospital is the organizing center.
 - i. Centralization of document ownership regarding donors
 - ii. Centralization of document ownership regarding products
 - 2. Consider if the blood centre/hospital is the hub for managing donors
 - a. Testing
 - b. Recruitment
 - c. Record keeping
 - 3. Consider whether the blood centre/hospital is the hub for managing products.
 - a. Storage
 - b. Freezing
 - c. Record keeping
 - d. Shipping
 - 4. Consider if the blood centre/hospital is the hub for managing patient testing and information:
 - a. Testing
 - b. Record keeping
 - c. Data sharing
 - d. Communication between centre and hospital staff
- C. Local Laboratory
 - 1. Consider role of non-blood centre, non-hospital laboratory.
 - 2. If you recruit, collect, process and distribute donor blood, see above sections.
 - 3. Consider if the local laboratory is the patient testing and information hub.
 - 4. Determine if differences exist between current policies and processes for routine patient's sample testing and testing involving patients requiring rare blood products.
 - 5. Determine if current processes and procedures are adequate for participation in rare donor registry.
- B. Document development
 - 1. Define roles of the participating entities.
 - 2. Develop memorandum of understanding (MOU) as required by institutions.
 - 3. Determine if partnership agreements are necessary.
 - 4. Define the collection and use of the consolidated donor and patient data.
 - a. Anonymous
 - b. Authorship
 - c. Database management

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Section IV – ISBT Working Party on Rare Donors Membership

When establishing a collaborative rare donor programme, working with the ISBT Working Party on Rare Donors can provide valuable information, templates of forms, and networking for rare blood products.

- A. ISBT Working Party on Rare Donors membership - Organizer
 1. Consider whether a central database is desired. If yes, it might be logical to have the organizer be located in the place where the database entry and retrieval occur in order to directly supervise the activity and have that person be nominated for ISBT Working Party on Rare Donors. See Terms of Reference for the ISBT Working Party on Rare Donors.
 2. Alternatively, consider designation of a Director for the Rare Donor Programme in the region starting the Rare Donor Programme and have this person be nominated for membership in the ISBT Working Party on Rare Donors.
 3. Consider the workload levels of staff involved.
- B. ISBT Working Party on Rare Donors of the National Society
 1. Within the participants and institutions, consider what size the National Working Party on Rare Donor should be based on number of interested participants or if that is needed.
 2. Develop Terms of Reference defining organizational structure, membership, responsibilities and duties.
 3. Ensure representation of the appropriate positions and levels.
 - a. Consider Medical Staff and Medical Consultants.
 - b. Technical staff
 - c. IT staff
 - d. Patient Advocate
 - e. Legal Counsel
- C. Government alignment/approval
 1. Consider liaison position for government alignment.
 2. Develop relationships with appropriate government staff.
 3. Determine if appropriate to be a subsection in the professional society
 4. Determine if development of Memorandum of Understanding (MOU) is desired with:
 - a. Ministry of Health or similar department
 - b. Ministry of Foreign Affairs or similar department
 - c. Ministry of Commerce & Customs or similar department
 - d. National/Dedicated Airline as required
- D. Review documents and tools available on ISBT Working Party on Rare Donors Webpage
 1. International Rare Donor Card Template
 2. Rare Donor Programme brochure template
 3. Antibody Identification Card for Patients template
 4. Flow chart Rare Blood Request (for request of rare blood from International Rare Donor Panel)
 5. Outcome of antigen positive transfusion form
 6. ISBT Working Party on Rare Donor Rare Blood Shipment Form

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7. Reference List
8. Case Studies
9. Links to International Rare Donor Programmes

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Section V - Determining Support

When establishing a collaborative rare donor programme, ensuring there is support available to the programme is essential.

- A. Testing laboratory capabilities
 1. Donor sample testing
 - a. Resources can be difficult to allocate to a new activity with no immediate reimbursement of expenses.
 - b. If no allocation of funds has been requested, that can be the first step.
 - i. Determine the cost of a batch of tests including reagents and supplies.
 - ii. Determine if workload allows dedication of some portion of technologist time for this new testing and data entry to store the information obtained.
 - iii. Determine how many batches can be performed in the time that is dedicated to this new testing activity.
 - iv. Calculate the costs of this new testing.
 - c. If there is not an allocation of funds immediately available:
 - i. Consider requesting resources from local, regional, national and international sources.
 - ii. Start keeping records of rare donor testing.
 - iii. Optimize a method for identifying rare donors
 - a. Use for identifying the returning rare donor.
 - b. Use for recruitment when that rare type is needed.
 - c. Consider contacting donor for recruitment and sibling testing purpose.
 2. Strategic approach to optimize rare donor identification
 - a. Base the approach on donor information:
 - i. Consider if there are types more prevalent in certain ethnic groups.
 - ii. Consider if immigrant testing is a possibility to identify rare donors based on the rare needs of the immigrant population.
 - iii. Consider if a low prevalence antigen is identified, testing for the associated high prevalence antigen.
 - iv. If a donor is identified, inquire about testing siblings.
 - v. If a patient requiring rare blood is identified, request siblings be tested.
 - vi. Base approach of the most productive testing.
 - a) Test donors who have donated more than one time.
 - b) Test donors drawn in parts of the region with population density of an ethnic population with more donors.
 - c) Test group O donors only at the beginning to maximize use of the donor blood.
- B. Location of testing laboratories
 1. Determine which laboratories can provide testing.
 2. Determine if other laboratories have more capacity in time or resources.
 3. Ensure testing laboratories have agreed to share reagents and when patient sources are involved, ensure consent is appropriate and anonymity of donor is secured.

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4. Review existing transportation schedules to optimize sample transport and decrease new costs.
- C. Patient's sample testing
1. Serologic testing
 - a. Determine if the samples will be tested in remote locations or in the facility hosting the rare donor programme or both.
 - i. If tested in remote locations, decide if the antibody identification testing worksheets and results are to be sent with the sample.
 - ii. Decide if referral form with information about the sample should be created for referrals to central laboratory.
 - b. Determine the requirements for confirming identity of antibody(ies)
 - i. Include the number of antigen positive, and antigen negative RBCs required for identification.
 - ii. Include if antigen status of the sample is to be tested.
 - c. Determine the frequency of repeat antibody identification
 - i. Frequency for confirming existing or historic antibodies if required.
 - ii. Frequency for ruling out the presence of new antibodies.
 2. Molecular Testing
 - a. When the serologic testing process is decided, determine how to integrate molecular test results, and how that will be shared and utilized for rare blood requests.
 - b. Decide if molecular prediction of antigen status must be confirmed serologically (when possible) for pertinent antigens for rare requests.
 - c. Define the situations where confirmation (if required) is not possible and molecular prediction of antigen status will be sufficient for rare blood requests.

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Section VI - Ethical Considerations

When establishing a collaborative rare donor programme, several ethical concerns must be carefully considered and addressed to ensure transparency, fairness, and the protection of donor rights. The key areas of concern include **donor consent**, **recruitment practices**, **genetic testing**, and **data usage**.

A. Donor Consent

1. Informed consent must be obtained from donors, ensuring they fully understand what participation entails, including any future uses of their blood or data.

2. Example: All individuals participating in the rare donor programme will provide informed consent prior to enrollment. The consent process will be conducted in a clear, respectful, and culturally sensitive manner, ensuring that donors understand the purpose of the programme, the procedures involved (including blood group genotyping), potential risks and benefits, and the use and storage of their personal and genetic information. Donors will be informed that participation is voluntary, that they may decline or withdraw at any time without consequence, and that their decision will not affect their access to healthcare or donor services. The consent process will include opportunities to ask questions, and materials will be provided in accessible formats and languages appropriate to the populations being recruited.

B. Donor recruitment

1. Rare blood phenotypes may be more common in certain ethnic or minority populations, which raises concerns about equity, representation, and potential exploitation. Ensure recruitment campaigns are culturally sensitive, inclusive, and community-informed.

2. Example text to use with donors: Participation in this program is entirely voluntary. We aim to recruit a diverse group of donors, including individuals from underrepresented communities, to help identify rare blood types and improve transfusion outcomes for all patients. You are being invited based on your potential to contribute to this important public health effort. Choosing to participate or decline will not affect your access to healthcare or any other services. We are committed to respectful, inclusive, and ethical recruitment practices, and you are free to ask questions or withdraw your participation at any time without penalty.

C. Genetic testing

1. Genetic testing may reveal sensitive information, including risks for inherited conditions, that donors may not wish to know or have disclosed. Disclose that blood group genotyping is genetic testing in consent forms — but explain its limited and specific purpose. Clarify that no disease-related information will be returned or uncovered through this testing.

2. Example text to use with donors: As part of this programme, we may perform blood group genotyping, which is a type of genetic testing used to determine specific blood group markers that are important for safe blood transfusion. This testing focuses only on genes related to blood group type and does not provide information about health conditions, disease risks, or ancestry. The

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results will be used solely to support blood matching and transfusion safety. While this is a form of genetic testing, it is limited in scope and does not carry the same privacy or health implications as broader genetic analyses. Your information will be kept confidential and used in accordance with applicable data protection laws.

D. Data usage

1. Ensure robust data security protocols, and limited access to identifiable information.

2. Example text to use with donors: The information collected from you, including your blood type, genotyping results, and limited personal details (such as age, sex, and ethnicity), will be used to support transfusion compatibility, improve rare donor matching, and may be used in unidentified form for research and quality improvement. Your data will be stored securely, and access will be limited to authorized personnel involved in the donor programme. No identifiable information will be shared outside the programme without your explicit consent. You may withdraw your consent at any time, and your data will be removed from future use to the extent possible. All data management will follow local laws and best practices for privacy and confidentiality.

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Section VII – Financial

When establishing a collaborative rare donor programme, having the required financial resources known and in place or in a plan is essential to success.

A. Resources for the Laboratory

1. Testing resources

- a. If the rare donor testing programme laboratory is an extension of the transfusion service, only non-routine reagents listed below will be additionally needed.
- b. If the rare donor testing program laboratory is a stand-alone laboratory, then routine laboratory reagents needed for antibody typing and screening will need to be supplied
- c. Non-routine reagents needed may include:
 - i. Rare red cells
Suggested sources include commercially provided panel RBCs, samples from test tubes collected from rare donors for routine donor testing, de-identified samples from patients, sharing of rare RBCs locally or through exchange programmes.
 - ii. Rare antisera
Suggested sources include routine commercially available antisera that can be used in tandem to identify rare donors (e.g. anti Jk^a and -Jk^b to identify Jk(a-b-) red cells, sample test tubes collected from rare donors for routine donor testing, de-identified samples from patients, sharing of rare RBCs locally or through exchange programmes.

2. Equipment/reagent support for testing laboratories

- a. For serologic testing, most laboratories can utilize equipment routinely supplied for transfusion service use.
- b. Some laboratories may find having equipment for Monocyte Monolayer Assay (MMA)(dry air incubator and microscope), flow cytometry, or molecular test platforms included in their equipment inventory is appropriate.

3. Unit storage resource

- a. If the rare units are to be stored in the liquid state, then dedicated routine red cell unit storage refrigerator with strict temperature controls can be used. As the Rare Donor Programme advances, they may find that in their population it is valuable to have some more common rare units available in the liquid state. Particularly if the units are able to be found routinely.
- b. Most Rare Donor Programs eventually find that having frozen units of less used but frequently required to be imported rare types is valuable.
 - i. The process of freezing using available commercial instruments is required.
 - ii. Freezers to support the freezing method chosen are required.
 - iii. Inventory must be carefully planned by location and by the expiration date.
 - iv. Most commonly, expiration dates are listed by the manufacturer usually as 10 years in the frozen state. For exquisitely rare units, Rare Donor Programmes designate a longer storage time, 30 years or indefinitely in the case of rare autologous units.

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4. Staffing

1. Medical Laboratory Scientists of high caliber with experience are often sought to fill testing positions in rare donor programme laboratories. This is useful for the non-routine testing that is frequently needed in complex antibody identification.
2. Commonly needed are staff who can perform routine serologic antigen typing and/or use semi-automated instruments to identify rare phenotypes.
3. The number of staff required is determined by the volume of testing and the hours of operation.
4. Consider developing training documents and tools.
5. Consider how competency will be established and maintained.

B. Transportation network and distribution process

1. Work with existing local transportation networks for in-region transfers of red cells.
2. Establish contacts and in some cases contracts with transportation vendors to transport rare red cells in the liquid or perhaps frozen state.
3. If international transport of red cells or other rare products is going to be performed (as in case with collaborating with the International Rare Donor Panel as a member of the ISBT Working Party on Rare Donors), then contact should be made with the government agencies of the country who regulate imports and exports.
4. Determine the documents needed to track donor transactions, transportation and use.

C. IT Support

1. IT platform support should be planned for securely storing donor information, donated unit Information, and patient information on rare needs and antibodies present.
2. IT Help support on and off hours for problems with the IT system.

D. Human Resources beyond the staff in the laboratory

1. Leadership
 - a. Identifying leadership in the areas of Medical, Technical and Administration for the program is essential.
 - b. Identifying by title a leader to the daily activities of the Rare Donor Programme is essential. Having a back-up leader when the leader is not available is most useful.
2. Members of the programme should be identified even if they have other roles in the organization.
3. Establishing a Liaison with ISBT Working Party on Rare Donors if membership has not yet been obtained is very useful.

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Section VIII - Confirming Need

When establishing a collaborative rare donor programme, information regarding the phenotypes of rare units that have been needed historically can provide valuable planning information for the future. Collecting the information below is suggested.

A. Units needed, not sourced in location

1. Collect information from participating centres regarding what ABO/Rh and phenotypes were not able to be sourced by the facility with the request.
 - a. This information will help determine the phenotypes that could be tested for with the units in inventory.
 - b. This information may also assist in determining phenotypes that could be frozen for a future need.
 - c. This information may also assist in determining known phenotypes that could be preferentially recruited for donation.
 - d. If these phenotypes are high prevalence antigen negative, it may also be useful to recruit siblings of the known antigen negative donors.
 - e. Collecting this information may also reveal needed phenotypes with an exquisitely rare phenotype.
 - i. It may be desired to recruit these donors and also to inform them of the very rare nature of their type.
 - ii. These donors might be considered for autologous donation and storage of units in the frozen state in case blood is needed for them in the future.
2. It may also be useful to identify chronically transfused patients who require rare blood to be prepared for future needs.

B. Most frequent rare types requested

1. Collect information from participating centres regarding ABO/Rh and phenotypes of the rare red cells requested.
 - a. This information will help determine the phenotypes that could be tested for with the units in inventory.
 - b. This may also help to determine if rare units should be held for a period of time in inventory for a possible need. The timeline for this storage should be locally determined based on inventory and usage data.

C. Define rare donor phenotypes for the Rare Donor Programme

1. Many rare blood programmes define a rare donor as one with an occurrence rate of 1 in a 1000. However, the definition is flexible and in the beginning of the Rare Donor Programme establishment, a rare donor may be defined as those phenotypes that are difficult to source.
2. As the Rare Donor Programme progresses, the phenotypes designated as rare may change.
3. ABO/Rh also plays a part in the determination of rare blood that is difficult to source. For example, the provision of k negative units that are A+ is likely easier than finding O negative red cells.

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Section IX – Communication

When establishing a collaborative rare donor programme, there is information to be shared that is helpful to start the programme, especially in collaboration with other facilities and the public.

A. Communication with Laboratory and Clinical Staff

1. Education of internal staff is critical to ensure communication with medical staff, donors, media and the public is identical.
 - a. Included in the internal staff list are the collection staff, manufacturing and production staff, medical doctors, and product distribution staff.
 - b. Education should include the purpose of the Rare Donor Programme, the benefits to the patients in the facility and region.
 - c. Some of the challenges have been seen in understanding why, if all donors are to be treated specially, why the Rare Donors are particularly needed. Another challenge to Rare Donor Programme is when a rare unit is needed for a non-rare request such as with type O negative red cells which may be in short supply.
2. Laboratory and clinical staff will be communicating with:
 - a. Patient's families for sibling donations
 - b. Donors to promote sibling donations and update donor contact information
 - c. Facility staff for unit requests within facility and with external facilities
 - e. The public through request for blood and media requests

B. Communication with Donors

1. Standard communication should be developed, reviewed and approved by technical, medical and public relations staff. Suggested focused standard communication are:
 - a. Random Donors with ethnicities more likely to have a particular rare phenotype.
 - b. Family members of patients requiring rare blood
 - c. Identified rare donors with possible topics of:
 - i. Materials to join the Rare Donor Programme as an identified Rare Donor
 - ii. Rare donor programme identification cards
 - iii. Recognitions and possible rewards or “badges” for donation
 - iv. Recruitment materials
 - v. Periodic update of contact information

C. Communication with the Public

1. Consider publishing human interest stories in public forums.
2. Consider publishing reports of progress in scientific publications.

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Section X - Alternative Approach When there is no official initiative to create a Rare Donor Programme

A. Situation 1. One professional individual starts the idea. A professional may identify the need to have a rare donor programme determined by their experiences in their facility or in hearing about case reports where rare blood was needed.

1. Seek other professionals in the same situation.
 - a. In their city
 - b. In their regions
 - c. In their country
2. Seek to establish some rare donor programme activity and interest.
 - a. Present to scientific society.
 - b. Seek other rule-maker support such as government or assessment agencies.
3. Financial support
 - a. Most often is supported by the facility who starts it and others who join the project.

B. Situation 2. Rare donor programme need is identified outside the facility or region or country. An expert may identify the unrecognized need for a supportive programme to meet needs. Or a medical situation may arise for rare blood that may call attention to the need. In this case it could be that a medical professional within an institution takes the initiative or it could be that an expert outside the institution is requested to assist in the project.

1. Research what support and resources can be available and obtained.
 - a. Governmental
 - b. Societal
 - c. Institutional
 - d. Grant funding