

## Implementation of the BATIK PELANGI Program through CSR by PT GSI Lab for Families of Rare Disease Survivors

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### Abstract

This research discusses the implementation of the BATIK PELANGI CSR program formed by the GSI Lab company and aimed at families of rare disease survivors. The purpose of this study is to explain the implementation of the program and the responses given by program makers, doctors, families of rare disease survivors, and explain the forms of social treatment contained in the program. This research uses descriptive qualitative research method. In determining informants, researchers used purposive sampling technique. Meanwhile, in this study researchers also used the social contract theory proposed by Jean-Jacques Rousseau in his book entitled "The Social Contract" and Stakeholder Theory proposed by Freeman. The results of the study explain that PT GSI Lab's CSR program, namely BATIK PELANGI, has the same intention as the social contract theory proposed by Rousseau, namely a business activity like a company does not only operate only to meet the company's personal needs, but must also think about the public interest. In addition, it is also explained in this study that the families of rare disease survivors are part of stakeholders, which are individuals or groups that have an interest in the establishment of a CSR program, so that they can influence or even be influenced by the presence of a company or organization in achieving goals.

### Keywords

Rare Disease, CSR, Survivors, PT GSI Lab

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## **INTRODUCTION**

In Indonesia today, rare diseases are one of the focus problems that must be faced by the government and Indonesian society. This is because there is a lack of movement from the government to deal with various cases of rare diseases in Indonesia. This is also caused by a lack of adequate medical personnel to deal with rare disease cases in Indonesia. Apart from that, the lack of public concern for rare disease survivors is also a problem that Indonesia must address at this time. A disease can be called or categorized as a rare disease, if the disease can threaten a person's life or be chronically debilitating with a rate of 5 in 10,000 sufferers in a population. Genetic factors are one of the causes of someone having a rare disease, and generally most of the sufferers are children or babies (Yang et al., 2021).

In Indonesia itself, the percentage of rare disease survivors is in the range of 8 to 10% or it can be estimated that there are 27 million survivors out of the total population in Indonesia. Around 80% of survivors of rare diseases are caused by genetic factors (Sarmoko, 2023). In addition, as many as 20% of rare disease survivors in Indonesia are caused by non-genetic factors which are influenced by environmental factors or during the pregnancy process (Adimas Raditya, 2023). Seeing the increasing number of rare disease patients in Indonesia, this has encouraged GSI Lab to try to help rare disease patients. From this initiative, a social program was born called BATIK PELANGI (Bantu Genetic Testing for Rare Indonesian Diseases), is a social program initiated by GSI Lab as their social responsibility to help the community.

Social responsibility or Corporate Social Responsibility (CSR) is a mechanism carried out by organizations or companies as a form of their concern for the environment and social, where in its implementation there is interaction between the company and stakeholders, and of course this exceeds the organization's responsibility in the legal field (Reni & Anggraini, 2006). The CSR program built by GSI Lab in the form of the BATIK PELANGI program aims to provide assistance to families and patients who are survivors of rare diseases. Meanwhile, some of these benefits are providing free genetic tests to patients, providing information about how to care for patients at home to families, increasing public awareness through social media, and inviting the public to participate in donation activities to help families and disease patients. Apart from that, it makes it easier for families and patients in the process of searching for or accessing medicines for the rare types of diseases they have. It is hoped that all these efforts will produce good results or developments for rare disease survivors.

In this research, the author focuses on researching the implementation of the CSR program carried out by PT GSI Lab through the BATIK PELANGI program for families of rare disease survivors. From this implementation, of course, researchers will look at how to implement CSR programs specifically for families and patients who are survivors of rare diseases. Of course, apart from how they implement the program, researchers also want to see the responses given by families and patients who have survived rare diseases. Because with these responses, researchers can later assess implementation. The program carried out by PT GSI Lab for families and patients who are survivors of rare diseases through the BATIK PELANGI program can run well or not. Apart from researching the implementation of the BATIK PELANGI CSR program carried out by PT GSI Lab, researchers also want to explain the benefits of social treatment that PT GSI Lab has provided to survivors of rare diseases who take part in PT GSI Lab's BATIK PELANGI program.

## **RESEARCH METHODS**

In this research, researchers use qualitative research methods, so that the results of this research will be in the form of descriptions of words or texts that explain phenomena or actions that occur in society. According to Arikunto (1998, p. 390) qualitative research is a type of research method specifically aimed at assisting researchers in collecting and describing information about everything related to the symptoms of a particular phenomenon being studied

while the research is in progress. Therefore, the use of qualitative research methods aims to help the author uncover the phenomena that the author aims for in his research, and with this method the author can also obtain the data or information needed for his research in depth (Rohimah, 2021). Meanwhile, in the process of determining informants, researchers used purposive sampling techniques. In this technique, the informants needed are informants who have the criteria determined by the researcher, namely the informant must be related to the researcher's research objectives, namely being involved in the BATIK PELANGI program.

The research location is located in the Genomics HUB Building, Setiabudi, South Jakarta. The reason the researcher chose this research location was because the researcher wanted to research PT GSI Lab's CSR program, namely the BATIK PELANGI program. Meanwhile, data collection techniques are the researcher's first step in conducting research as a form of the researcher's efforts to obtain the data and research information needed by the author. This technique is also a step for the author to complete and organize his research systematically. Therefore, seriousness and thoroughness are needed to compile and collect the data that the author needs as material for discussing his research. Of course, to obtain the necessary data, the researcher must carry out several stages, starting from conducting observations and interviews to collecting documentation results that the researcher has obtained after carrying out field activities. These things are very necessary for the smooth and successful research process carried out by researchers to complete the research results.

Researchers used the Miles and Huberman model data processing and analysis techniques in this research. Data analysis carried out by researchers took place during collection and after completing data collection. This is a form of the researcher's efforts to search for, organize, and formulate conclusions systematically from the results of the stages or process of interviews and observations carried out directly by the researcher. Qualitative data analysis is a form of analysis that does not use mathematical or statistical analysis. The data analysis carried out by researchers is also limited to data processing techniques, which the authors then carry out descriptions and even interpretations of their research. Meanwhile, several of Miles and Huberman's concepts used in this research are data reduction, data display, conclusion drawing, and verification. Meanwhile, in the concept of drawing conclusions and verification, there is a data validity testing process, which is useful for ensuring that the data obtained by researchers when carrying out field activities is correct, trustworthy, and relevant to the research focus.

## **RESULT AND DISCUSSION**

In this research, researchers made observations at the GSI Lab, precisely in the Genomics HUB Building, Setiabudi District, South Jakarta. GSI Lab also known as PT. Genomics Solidarity Indonesia is a company operating in the health sector. This company was founded in 2020, precisely during the COVID-19 pandemic, which was hitting Indonesia at that time. Meanwhile, the establishment of this company at that time was specifically to help the government and society to overcome the COVID-19 pandemic that was hitting Indonesia at that time. The assistance provided by this company is in the form of a PCR testing laboratory and Antigen Swab tests.

As time went by, the Covid-19 pandemic began to decline, so PT. GSI Lab must build a new idea in order to survive. For this reason PT. GSI Lab strives to create new CSR programs that are beneficial to society. Of course, the programs created will remain focused on the health sector. Meanwhile, the new CSR program created by PT. GSI Lab is called the BATIK PELANGI (Help in Genetic Testing for Rare Indonesian Diseases) program. This program was founded on the basis of the solidarity movement which was the aim of the founding of the GSI Lab and concern for cases of rare diseases in Indonesia. The realization of the BATIK PELANGI program does not escape the existence of a certain logo design to indicate or give

meaning to the creation of the program, and of course each design has its own meanings that can be explained. The following is a picture of the BATIK PELANGI logo and an explanation of the meanings of each logo design.

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**Figure 1.** BATIK PELANGI logo (Source:PT GSI Lab)

1. DNA  
There is an image of DNA in the logo above, where DNA is described as something that is inherent and owned by living creatures, and it is this DNA that makes each living creature have its own differences.
2. PARANG KUSUMO  
Parang Kusumo is a batik motif which means that life must be based on or accompanied by struggle as an effort to obtain inner and outer happiness like the fragrance of the Kusuma flower.
3. WHITE COLOR  
The white color in the logo is symbolized as the beginning of a new cycle of life,

which also explains that a better life will begin.

4. STRAIGHT LINE

The straight line in the logo is symbolized as a form of equality and justice, which means that even though they have differences, they have the right to receive the same attention and treatment equally.

5. COLORS OF THE RAINBOW

The rainbow colors contained in the logo design have their own meaning for each color, namely red means life, orange means healing, yellow means sunlight, green means nature, blue means art, purple means harmony.

6. BATIK PARANG

Parang batik in the logo means human consistency in improving themselves from time to time, having an unyielding spirit and the enthusiasm to always fight to achieve inner and outer happiness in life.

Meanwhile, several stages have been carried out in the running of this program, starting from the opening of the program to the running of the program to date. In the initial stages of program implementation, GSI Lab held a launching event for the BATIK PELANGI program, which was held as a sign that the BATIK PELANGI program was officially opened and running. Then, at the event there were of course several speeches from the GSI Lab and several representatives from the rare disease community. Apart from that, there was a sharing session conducted by several families of rare disease survivors, where this sharing session was intended to listen to the complaints of the family's journey in finding a diagnosis and appropriate treatment for their family members.

After going through the program launching event, of course it continues with the process of taking blood samples to carry out the process of diagnosing the types of rare diseases that rare disease survivors have. This process is of course carried out in turns one by one for each patient. For this stage, patients who have been registered in the GSI Lab company data records will be called, and in this calling process there will be one to two patients who will come to the sample collection location a day. Meanwhile, the location for taking patient blood samples was at the Genomics HUB Building, South Jakarta.

The next stage is that if the diagnosis of a rare type of disease that the patient has is known, the family will be contacted again. The aim is to provide information regarding the dissemination of appropriate care for the type of rare disease the patient has. In the socialization process, of course, doctors from the GSI Lab were accompanied by those who took part in the BATIK PELANGI program. In this socialization process, doctors have an important role because they are experts who have knowledge about rare types of diseases, along with appropriate treatments to treat the types of rare diseases that patients have. That way, the patient's family can find out which treatment is suitable for the patient and can easily find the needs the patient needs for his recovery.

Meanwhile, from the process of starting the program which started with the launch of BATIK PELANGI until now, the GSI Lab has invited the public to participate and contribute in helping families and patients who are survivors of rare diseases. This was done by the GSI Lab through the outreach they carried out by utilizing their social media by disseminating various information related to rare diseases. Apart from spreading information through social media, GSI Lab also opens donations to help families and patients who are survivors of rare diseases. Of course, in carrying out this donation activity, GSI Lab does not act alone, they collaborate with good seed platforms to carry out the donation.

Of course, the implementation of the CSR program carried out by PT GSI Lab in the form of the BATIK PELANGI program received a lot of good responses from patient families and the public who care about rare disease cases in Indonesia. Apart from the patient's family

and the community, good responses were of course also conveyed by internal parties of the GSI Lab company regarding the implementation of the BATIK PELANGI program, namely doctors and program makers. Of course, the response given from both parties also seemed quite good, because both of them were proud of the formation of this program. They said that their concern about the problem of rare diseases was increasing. This happened after they interacted with families and rare disease survivors. Because they become more concerned because they listen to various complaints about travel families and patients in getting treatment along with an accurate diagnosis of their rare disease.

There were several good responses given by recipients of the BATIK PELANGI program after researchers conducted interviews with them. The first response came from a husband and wife who has a special needs child with the rare disease Rett Syndrome, they live in the Banjarnegara area, Central Java. After participating in the BATIK PELANGI program they felt happy as seen from the responses given by their mother in the interview session as follows:

*"I am very grateful, very grateful that at least there is an opportunity, so our minds are not looking for why, why. All this time, we have been confused, the doctor hasn't even explained why this is, what is the cause of this, we are still just guessing. Having this program really helps us."*

Apart from that, they also felt happy because the services provided by the implementation of the program were all free of charge or free, ranging from genetic tests, consultations to medical assistance. Of all that is provided by the BATIK PELANGI program, of course they hope that in the future the BATIK PELANGI program can continue to develop and help patients who are survivors of rare diseases in Indonesia. This was conveyed in the interview session as follows:

*"Hopefully we will continue to provide opportunities for other parents who have special children like ours, to be given the opportunity to undergo a free WES examination, because this is very, very helpful."*

Meanwhile, the two parents also expressed their concern for parents out there who have the same fate as them, according to them everything that God has given us is a gift that we should be grateful for. We as human beings must not despair, be disappointed or be discouraged from accepting whatever God has given us. Likewise, we as parents who have children diagnosed with rare diseases must not feel inferior and must not be ashamed. In fact, never make it seem as if the child's presence is not wanted, as parents we should provide more support to the child and give the child the best, and must always remain enthusiastic.

The second resource person is a husband and wife who have a child with a suspected diagnosis of the rare disease Achondroplasia. They come from Jambi and now they live in Jakarta, they are also beneficiaries of the BATIK PELANGI program. After learning about the implementation of the BATIK PELANGI program which was formed by the GSI Lab company and participating in it, of course the mother's response was very grateful and felt helped, moreover this program is free for patients who are survivors of rare diseases, the following are responses from researchers' interviews with resource persons who received the BATIK PELANGI program :

*"I'm relieved, because I know for myself the payment, genetic testing is an extraordinary amount of money, we have always been advised to take genetic tests with Prof. Safe Pulungan. At that time he was still chairman of IDAI (Pediatricians Association Indonesia), because it is Achondroplasia which is different from Achondroplasia in general, so LG was told to check chromosomes, check genetics, I just said that the budget problem at that time was that BPJS didn't cover such checks, so when the community launched this activity it worked Same with GSI and BATIK PELANGI, we*

*immediately welcomed it with pleasure. Yesterday there was a similar activity but for the CMA type that was in Prodia, he didn't pass because he had to do this WES which is even higher. If yesterday he didn't pass because it would be a waste, that's why when there is WES This is progressing again, I'm just happy because I know more firmly how to enforce the diagnosis."*

From the results of the interview, it can be seen that the mother's happiness was being able to get the opportunity to take part in the BATIK PELANGI program held by GSI Lab. Apart from that, in the interview session the mother also gave her support for the progress of implementing this program so that it can help more and more patients diagnosed with rare diseases as follows:

"If I say that the BATIK PELANGI program will hopefully become even more advanced, more and more people will know what BATIK PELANGI activities are, and more and more donors will come in so that the activities can continue continuously and continuously. Hopefully BATIK RAINBOW will be more successful and will spread its wings even more.

Meanwhile, the impression and message given by the mother is for parents out there who have the same fate as her, which is that you should never feel sad about what God has given you, for example, like a special child, and this also indicates that parents Those who have children with special circumstances are also special parents. God gives privileges, so God believes that parents will be able to face and live with it, because whatever God gives us is good for us and whatever condition the child is given by God, there will always be a way if it is based on full faith. From this belief itself, opportunities and ways of sustenance will be created for parents.

The third resource person is a resource person who received assistance from the implementation of the BATIK PELANGI program. The resource person is a mother who has a child with suspected ataxia. Currently the mother, husband and child live in Yogyakarta, and the mother is a teaching staff at the university level or is known as a lecturer. After learning about the BATIK PELANGI program, the mother was enthusiastic to take part in the program and had the opportunity to take part in the program. Of course, the response given by the mother regarding the implementation of the BATIK PELANGI program was very positive, this was proven in the researcher's interview session with the mother, the following are the results of the researcher's interview:

"We are very grateful, because we have been given this opportunity because I am sure there are many out there who need it and we are the ones who were chosen and are really that excited to be able to come here. The explanation was quite detailed, including sometimes Doctor ZY gave statements that made us feel calmer because as parents, if we were told that we had a genetic disorder, our thoughts would be oh, that my child can't be cured because there's no cure. But good explanation, *Then being able to calm down is actually really extraordinary because it makes us parents live it so calmly.*"

Of course, behind the joy and happiness of the mother and husband for their child, they also hope that the good intentions of GSI Lab through the implementation of the BATIK PELANGI program will continue to develop and of course can provide benefits to many people, especially rare disease patients. This is stated in the researcher's interview with the mother as follows:

"The hope is that BATIK PELANGI can reach all of Indonesia, including in the regions. I'm sure there are lots of mothers out there who are also struggling and hope that their children will also be helped, because they get care from other people and then that help is also really needed so that

mothers- "The mother who is a genetic disorder survivor doesn't feel that alone either."

Apart from the mother's hope for the BATIK PELANGI program to continue to develop and be successful, she also did not forget to give an impression and message to parents who have the same fate as her. He said that we will not be alone, because God will always be with us. Whatever God gives us definitely has a good meaning for us, whether we will become better people, become stronger, what is clear is that in this life we live not only to have fun, but in this life we also have to fight. to become a better person.

In the BATIK PELANGI program there are several forms of social treatment that are specifically or given to families and patients who are survivors of rare diseases. Following are the 3 types of social treatment in the BATIK PELANGI program along with explanations.

1. Patient Care and Family Support

The BATIK PELANGI program aims to help families of rare disease patients by providing easy access to medical care. Of course, the medical treatment carried out is also assisted by the medical team from GSI Lab, where the medical team also has experience and knowledge about how to treat and care for rare disease patients. That way, the patient's family can rest assured about the care provided by the GSI Lab medical team, and of course this treatment can have a good impact on the patient's health condition, so that in the future the patient can get a chance to live longer or even have a rare disease that can be cured.

2. Increasing Public Awareness

Apart from providing consultations on how to treat from home, the BATIK PELANGI program also helps patients by increasing public awareness of current rare disease problems. GSI Lab is trying to carry out crowdfunding activities through their collaboration with the Benihbaik.com platform, where the funds from the crowdfunding will later be channeled towards medical assistance costs for rare disease patients who take part in the BATIK PELANGI program. Meanwhile, in an effort to increase public awareness, GSI Lab is collaborating with private media to help socialize the BATIK PELANGI program, so that later it can be widely known by the public. Of course, the hope is that from these efforts, the public can understand and make them more concerned about rare disease problems.

3. Genomic Testing

Genomic testing is also included in the form or effort in the BATIK PELANGI program to provide assistance to patients who are survivors of rare diseases in the form of WES (Whole Exome Sequencing) genetic testing. Of course, the genetic tests provided by GSI Lab to rare disease patients have a high level of accuracy in diagnosing the type of rare disease the patient has. Meanwhile, in Indonesia currently only GSI Lab has this genetic testing kit, so it is hoped that the BATIK PELANGI program will be very beneficial for rare disease patients, and it is hoped that it can also provide joy and pleasure to the families and rare disease patients themselves.

Corporate Social Responsibility(CSR) is a program, event or activity formed by a company voluntarily as a form of their concern for society. CSR established by companies is also a form of improving the quality of life of the community so that people can be skilled and receive benefits from these activities, so that they can respond to social conditions in society, and companies and communities can work together to improve the quality of environmental sustainability. wide (Ernawan et al., 2014).

GSI Lab as a private company operating in the health sector has the initiative to establish a CSR program, which is intended or specifically to help families and patients who are survivors of rare diseases in Indonesia. The reason the company is implementing the BATIK PELANGI program is because the problem of rare diseases in Indonesia is currently still a problem that

must be paid attention to because until now the attention of the public and the government regarding this problem has still been largely ignored. Moreover, many of the families and patients with rare diseases come from families in the lower middle class. Thus, it can be seen that the BATIK PELANGI program is included in a CSR activity specifically for people who have rare diseases.

Judging from the aims and objectives of the BATIK PELANGI program, which is a CSR activity and was formed by the GSI Lab company, it indicates that the company has carried out a social contract through this CSR activity. The social contract theory according to Jean-Jacques Rousseau in his book entitled "The Social Contract", states that there needs to be an agreement from several individuals to form an alliance based on the needs of society. This is in accordance with the BATIK PELANGI program which is a CSR program formed through an agreement between individuals with the aim of helping meet the needs of society, especially families and patients who are survivors of rare diseases in Indonesia. Of course, if the basic basis for establishing a CSR program such as BATIK PELANGI is in accordance with the social contract theory presented by Rosseau, then in the future, after families and patients with rare diseases get the needs they want, a sense of brotherhood can be created between the parties or individuals. within the company to families and patients with rare diseases.

Of course, the role of stakeholders in this program is very important for the progress of the program. Therefore, a CSR program is formed because of the company's sense of responsibility to the community, where this community is part of the stakeholders. In stakeholder theory or stakeholder theory put forward by Freeman (1984) explains that the company is one of the organs within it there is a community scope and there are relationships between interested parties, whether relationships with internal parties or external parties within the company within the community scope. Stakeholder theory assumes that a company needs support from stakeholders, where as stakeholders become stronger, a company will also have more business needs that can be used to adapt to other stakeholders. Therefore, in this case program makers, doctors, families and rare disease survivors are among the stakeholders who can help the company achieve its goals and help the BATIK PELANGI program run.

## CONCLUSIONS

The conclusion from the results of this research is that the researcher concluded that the implementation of the BATIK PELANGI CSR program of the GSI Lab company was carried out well from the initial stages of the program, namely the launching event, to the current stage, namely providing socialization on home care methods to the families of patients whose illnesses have been diagnosed. Meanwhile, the response was good from the program's beneficiaries, namely the families of rare disease survivors. Many families expressed their gratitude to GSI Lab because of the BATIK PELANGI program, and they also hope that the BATIK PELANGI program can continue to be implemented well in the future. Then, from the social treatment provided by the GSI Lab company through the BATIK PELANGI program to families and patients who are survivors of rare diseases have quite a good impact, because from this social treatment the beneficiaries can be greatly helped. Meanwhile, the form of social treatment provided is as follows:

- 1) Patient care and family support, which aims to provide easy access to medical care for patients, as well as improving the skills of the patient's family on how to care at home.
- 2) Increasing public awareness, namely GSI Lab collaborating with private media to help spread the BATIK PELANGI program, as well as collaborating with the Benihbaik.com platform as a place for the public to donate and later the proceeds of the donations will be used to help patients.

Genomic testing, namely providing genomic testing to facilitate access for patients who need genomic testing as an effort of the BATIK PELANGI program to end the patient's diagnostic

journey in seeking an accurate diagnosis regarding their rare disease.

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