

In the name of God

The Birth of a Butterfly



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Preface

This is the true beginning story of someone who never gave up even for a single moment. Born to be a real pioneer. Since childhood, carried the weight of the term "A Man" on his shoulders. He had his childish tastes, but not the same as those of the children around himself. Since he was today where his eyes could look upon tomorrow, for him any sign had got the right concept and color. And the last sign as a touchstone in his world, ended up to these lines, meant a lot to him. The story of a man who could turn a small sign into a main goal ever been and could illuminate the dark and fade spots of good people's life of his homeland, yet innocent and fresh alive.

Wishing the ins and outs of each breath could touch this shining light.

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The BIRTH OF A BUTTERFLY

It was one of his busy days. He was coming back from a meeting and the street was full of cars as well as the people in the sidewalk. Too many people and lives! While driving, he had a short glance at them. A honking horn car turned among the other ones and trapped at the red light and heavy traffic and another car horn pushed the front one inch ahead itched his ears. He pulled himself together and said to himself, "How people's driving looks like their lifestyle!" Some know how to turn or to derive away and some believe how to make an opportunity or to move on, anyway. As it turned green, he moved in a by-street he loved so much through which he had passed a lot and the street always filled up his senses as if they were old friends for long. Missing the trees in North, his homeland, he fondled the trunk of green trees of his old friend. Like every day, he greeted with nodding his head as turning to get into the parking toward the greengrocer at the corner glowing fruit skin with a cloth and a smile on the face.

He preferred walking up the stairs than riding on elevator. Stopping by the imaging center hall, he used to greet everyone. He felt quite nice as found the floor clean and so shiny at the center. Everything was in its place, tea bags, water coolers, cube sugar and chocolates. And also the wheelchairs for emergencies by each room. He felt quite nice now! Everywhere was full of light Oud scent as per his order. He deeply liked the gentle flow of cool air in summer and warm in winter which welcomed everyone. The staff stood up and greeted him one by one and he knew they counted him as their caring father more than being their boss even if he would give them a serious reminder.

Instead of shouting at someone for a mistake or irresponsibility, he could control his temper and indirectly talk sarcastically; then the fallible made his or her account. He was satisfied with everything which was in order. The caring father used to inspect and check each room and section at the center so early each morning while the night shift staff still in there and also socialized with staff, doctors even affable and smiling watchmen and guards at the entrance door and even the last person at the last floor of the building. To him, the imaging center was just like one of his children of which he should take dateless care; floor by floor and room by room. Many people referred the imaging center every day. Some in rush, some walked slowly getting in and he was just watching and found his shoes so shiny and waxed. He was well dressed like always and they all went with him.

That morning, had the dark blue suit on with stripes and also a light blue shirt. He loved the harmony in colors, indeed. He looked at himself in the mirror. He was dressed perfectly, like always he loved to be so. Turned his eyes on the people came in and out, he fixed them on a point. He was flinched as if fell off a height. Tried to pull himself together and he walked up the stairs. No more sign of the good sense and feeling. All was gone some minutes ago. He got into his room directly, but he could not hear the secretary greeting him.

She was astonished and waited for his reply. He took off his coat and while sitting on his chair, gazed at the stripes on his coat as if had discovered something strange. His mind was somewhere else. The Oud scent became stronger and his room had gracious atmosphere over there. You had to enter the secretary room; then you could find his cream soundproof door with golden lines in harmony with the wall paper. This room was L-shaped with two tables, one bigger for important meetings, the smaller for 4



people meeting sessions and finally his desk. He was supposed to cover the mess roof behind him with artificial grass, fully green like northern paddy fields.

He had ordered grey chairs for the conference table and his own desk, but they had not gone with the room decoration. Thus he asked to change the cover of chairs into turquoise blue. The seller was doubtful about his choice in color and put the catalogue on the table. It seemed tawdry color but when they were set around the table, he got all right. The seller had found him so daring not only for a choice in color, but for any act he performed. The harmony, soulful design and scent of Oud made the guests cheerful and fresh. He put his head on the desk to relieve. The thoughts rushed more and more and the room whirled around his head.

Looked at the room which seemed strange to him and asked for a tea and forbidden to let anybody in to concentrate more and start his daily job but of no use! What he had seen, was gone through his soul and insight. He kept the tea cup in hand so tight maybe to get warm and gazed at a little far distant point. His mother's voice was ringing his ears. She was talking about his sisters and brothers, while her sad voice became like a sore in her throat.

The image of her children was flashing before his eyes. A jam in his heart with deep sorrow and fear. Hamed, his assistant, was standing in front of him, surprisingly. He didn't hear Hamed's knocking the door several times and he got worried and stressful. He had the dark and cold tea glass in hand while staring his eyes at unreachable point. "What's up?" Hamed asked him. His answer was negative. What could he say? What he had seen made him just to open an old wound. Nobody could express and understand the concept. His mouth and throat had become dry and bitter. Now he came to know how much thirsty he is. Took the cup to his lips. The tea was cold. How long had it been since he came in the room and drowning in his thoughts? He put it on the table so slightly and let his fingers leave the cup while could not get rid of his thoughts. His mind was wondering like sands in the wind, scattering everywhere. Something deep inside was implied, "What is it, man? Thousands of patients come in and go out the center per day. Cured or not, why you are this much confused? ... Pull yourself together!" The vision was dancing in front of his eyes again. He had not seen such blisters before. The mother had brought the innocent kid with those scars on the skin to his clinic for the first time. His mind was all busy with the little kid. The only thing he could do was to call the reception and ask them to bring that patient's file to him and charge it for free.

Since the establishment of the imaging center, he avowed himself not to get away from the patients could not afford to pay and the reason was his promise to his parents as if he had become rich enough someday, he would have to do his best for everyone since most of the people and children of his village died at their birth because of poverty and lack of living facilities. Yet what he had done by today, did not pacify him anymore. He walked across and along the room to find a way and a solution for the kid and patients of this kind. There are many questions rushing into his mind. "How many children? How many adults are suffering from the disease? Is there a treatment and medication? How much are the prices of the drugs? How much do they have to pay for medications per month?" Discounting fee for medical visit for the kid was not the last and best solution. Suddenly, it popped into



his mind but at the same time his flesh shuddered of the big thought. They brought him the file and he called the shift doctors, Dr. Edraki, Dr. Najmi and Dr. Nasabi and discussed the details about the kid. Each of them explained him about the disease and same cases. They believed," The children are much more exposed to this disease. There are about 8000 types of rare diseases in the world. No Certain cure has been found and out of 10,000 people, 5 are suffering. Besides, the drugs are too expensive." He used to be in the heart of the society and had been interactive in medical services centers all over the country but it was the first time he heard about such diseases.

His feet made him to sit down but his mind was not free; yet it seemed that people did not know about it and I did neither. The blind spots with the disease signified themselves. The answer was hidden in the question. There must be some who would know about the disease and to inform people. Definitely, many doctors were familiar with types of these diseases but public awareness was something else. He relaxed himself on the chair, but rush of thoughts came again. He sheltered in his office for hours. He had done several creative civil projects in Iran, but they were all for medical purpose which was performed before. "When is it achieved for rare diseases? What are their names? Rare diseases only? It is innovation not creativity." he thought. He did not know where to start. So helpless to keep his mind and heart calm but to give up himself to God to relieve. He had asked the secretary not to let anybody in. She came in and told him "Hojjatollah Masjed Jameie has come to see you." As usual, he went out to respectfully welcome him, Mr. Masjed Jameie entered with dignity and self-possession of his own, like always.

Due to his international achievements, he set forth what he had seen and began an introduction about rare diseases for his acknowledgement. He explained about the European and American foundations which support the rare patients. Not more than some hours passed and he could find a lot about the different aspects of the matter. After Hojatollah Masjed Jameie left, he felt that the bright side is shining, slowly as if the pieces of the puzzle were coming to be matched. He had made his most for others and the patients, especially he knew about the sketch and the headlines yet not the starting point. While reminding Hojatollah Jameie's words and global careers from one side and the American and European countries approaches from other side, it was going to be totally more different jobs than others by the time being and he could not do it alone. It was supposed to be a big idea. He was sure he would need some specialists in different medical fields to assist and support him. As he saw the child till this moment any of his thoughts and experiences were measured as his touchstone, but to perform such magnificent career. There was many a way between mind and deed! His religious background since childhood was still generating through his life; therefore he should refer to his religious references and take the clergymen advice and in case of confirmation, asked for his success.

¹ Hojjat-Al Islam Masjed Jamei, President of the Institute of Islamic sciences and culture of the Islamic propagation office.



He called ²Ayatollah Golpayegani's office to ask for an appointment; therefore he should drive to Qom, immediately. He felt a deep delight inside along the way, for any economic, cultural and medical achievements he had made were helping him to stair up and reach the highest point to imply as if he were born to perform his mission, really. His eyes were on the road and was arranging his plans along the way. The road was longer than the last times. Arrived Qom with a bit delay and was eagerly taking the steps forward. This turned to be a new sense to him. No matter how much tired he was since the morning. He met Ayatollah Golpayegani who was one of the best with whom he used to consult. Of course they had things in common. Ayatollah Golpayegani used to be helping people with their healthcare for 50 years. Also he had established a hospital. He got more confident and determined after taking his advices. He went to ³Hazrat Masoumeh Shrine at which the lights shining as if his heart were getting brighter as well. He started his prayers, persuading the holy Hazrat Masoumeh to lead and help him with the big responsibility he was about to begin. He should get Tehran quickly as possible.

Against his wish, he left there and moved back to Tehran to meet with ⁴Ayatollah Nazari Khadem-ol-Shariat, the day after. The road was pitch-dark but his heart was so bright in deep. He was to begin and start the way ending up to the main goal based on the God's grace and beneficence. At midnight, he was not tired and it seemed too strange to himself as well. His power has doubled and felt too much excited. He knew the great days were coming and could not sleep by Morning Prayer. He was just thinking how to start. Whenever he felt anxious and confused, he used to give up and promise to his merciful God.

After having his breakfast, he moved to ⁵Mazandaran. Along the way, he was thinking of making progress. He was used to driving the same road several times for opening ceremony of the economic, cultural and medical projects in different cities of Mazandaran, but this time everything was totally different. Something deep inside was reminding him that this work is invaluable and could not be compared to any other ones.

It was about the noon he joined Ayatollah Nazari Khadem-ol-Shariat and discussed about his plans and goals, accordingly. The clergyman explained him the religious philosophy and justification in this regard: "The world depends on the movements and it requires big changes, firstly." He took a glance at his eyes and asked him: "Religions logic and nature wise approach indicate that human being is not for nonexistent purpose but for obtaining eternity and what should he do for his eternal life? He must get rid of money and fame."

² Grand Ayatollah Mohammad Reza Golpaygani was an Iranian Shia cleric and marja.

³The Shrine of Fatima Masumeh is located in Qom which is considered by Shia Muslims to be the second most sacred city in Iran after Mashhad. Fatima Masumeh was the sister of the eighth Imam Reza and the daughter of the seventh Imam Musa al-Kadhim.

⁴ Religious activist in Mazandaran province of Iran

⁵ It is an Iranian province located along the southern coast of the Caspian Sea and in the adjacent Central Alborz mountain range, in central-northern Iran.



Of course wealth and fame are considerable in life but if we spend our lifetime without any morality and welfare intentions, we are making a big mistake instead. You know the only path to eternity is just serving people as human beings, heal their wounds, saving people's life and treating their pain and making solutions for their life. The only justification in this regard is that human beings are God's successors on the earth.

Again, he gazed at his eyes and face and kept on saying a little more emphatic: "Whatever happens on your way, you have to be steadfast, and God will bless you, always." Ayatollah Nazari's words motivated him to be much more determined and now he has the power to overcome the unforeseen obstacles holding his goal. He also made another appointment with ⁶Ayatollah Abtahi over there. It was his habit to consult with these three holy clergymen before making big decisions. Ayatollah Abtahi also approved his plan the next day since he himself was pioneer in supporting such welfare careers. While explaining his plan and goal, Ayatollah Abtahi listened to him very carefully, for he was quite familiar with his spirit and determination; therefore he deeply encouraged him to consistently perform the plan. He felt so confident to begin as he had got his 3 trustees approval to his idea to initiate. With a deep enthusiasm, he began his work. Considering that any problem may change to be a turning point later on, he decided to be patient and consistent. He would have to refer many official executives and organizations. He met with old friends and colleagues; also found new friends in the meantime. Some encouraged him; some made him disappointed with pushing obstacles in his way. He could not understand why, since it was not his style and method of friendship. He used to help others to be on the run and progress. Some did their best in manly manner and took his hand. He had promised his God not to give up his deed for the sake of the little innocent girl and other patients.

About 18 months passed and he was succeeded in establishing "Rare Diseases Foundation of Iran" in winter 2008 after suffering a lot. It was newly established and there must be qualified and efficient policy makers to manage the plans and objectives. He always believed in consultation and asking others' view points and ideas for better decision, afterwards. He appointed RADOIR's policy making council and built up long meeting sessions and gatherings to manage the affairs perfectly as possible.

National and international counterparts' investigations, surveys and revisions were required to ignite the big task and action. There was not scaled statistics of rare patients inside the country. No public and no healthcare system controlling issues with rare diseases were available. On the other hand, he should find the global definition of rare diseases and its categorizations which was totally different from that of for specific diseases and was based on the infection rate to the total population of world's countries and nationalities. Considering many diseases could

⁶ He is an Iranian theologian, scholar, pro-democracy activist and chairman of the Institute for Interreligious Dialogue. He is a former Vice President of Iran and a close associate of former President Mohammad Khatami. Abtahi is a member of the central council of Association of Combatant Clerics



be counted as sub categories of the same diseases, every step would make another one and a heavy responsibility since the task was not such easy he had thought. He discovered he had to proceed the work nationwide and internationally. Firstly, there should be a little for disease to be defined for healthcare system inside the country in order to raising public awareness. Afterwards, they could estimate the infection rate and prevalence. Significant planning was done and the expertise specialists were invited to share the work. After one month, RADOIR should have an address; therefore without any hesitation, he located the head office of RADOIR in two flats of his own which were in the same building. He was doing his plan one by one to reach his great goals and objectives. There were two offices opposite of each other. One was his own and the other for the executives and referees. The opposite one belonged to the administrative, financial affairs for the patients.

By the way, I forgot to introduce him! Who he is. His name is Ali Davoudian. Of course they used to call him ⁷ "Haj Agha". On the occasion of ⁸Imam Reza (peace be upon Him) birth day on 11th ZiQa'ad 1430 (Arabic Calendar) equals to 30th Oct., 2009, he held a ceremony with the presence of holy clergymen, doctors, specialists and some of the official authorities at which he announced the establishment of RADOIR. He explained about the mission and future plans for rare patients and expressed his deep hope and ambition to make the authorities motivated to serve RADOIR in order to fulfill its aim and to achieve its main objectives in return. During a short time, all at RADOIR started their search for information through the relevant websites references but they discovered that the global references were also the beginners in the case of rare diseases. He believed that the first idea might pop up from somewhere else, yet the important thing is to make the ideas processed, practical and localized through creativeness, they could create innovative ideas and patterns to even reach benefits to other countries.

Mr. Davoudian was determined to acknowledge the authorities and raise public awareness for this type of rare diseases and even they could not do anything, they had to have an optimistic view on the rare diseases patients and sympathize with them. Maybe the concept of "Rare Diseases Patients" can make any responsible, organizational authority, individual decide to help and assist them and they can receive services and medication support in return while revising through the European and American online references, he came to know that each year; the universal federation celebrates "Rare Disease Day" on 24th February all over the world in different ways. Dr. Davoudian decided to tribute this day in Iran in the best and gorgeous way ever been since he was sure that he could fulfill his enthusiasm, accordingly. On the other hand, there was not left too much to the event and he never wished to miss this opportunity neither for himself nor the patients. He had to save the time or the worth of this great task, or it would be of no use if gets late like those of delayed before. Thus he called for all staff's will and determination to

⁷ It is a title which is originally given to a Muslim person who has successfully completed the Hajj to Mecca.

⁸ The eighth infallible Imam of Shia



begin their job. Due to his previous experiences, he should hold the event at the early establishment of RADOIR. Finally, it was the opening day of rare diseases in 2009 at amphitheater of Beheshti University. All supposed to join, was present. Unbelievable crowd! He was in his special style and too satisfied. Full of anxious but he was sure he will make owing to God's grace up to this moment. He was talking to himself, "Ali Davoudian! The wounds on the innocent kid's hand were just a sign to decide and to open the way. Be careful not to forget and miss the signs!" He was full of stress despite the nonstop efforts and dedication by the staff during a short time and holding out the ceremony as well as finding out who comes in the hall. Everybody was on rush and move. The opening ceremony started with the "Holy Quran" recitation, the official speeches by doctors, clergymen, authorities and artistic programs were all done on time.

Now it was his turn to deliver his speech about the foundation establishment as the founder and the father of Iran's rare diseases. He had forgotten to prepare any note for his speech. What should he say now? He got everything out of his mind with too much concentration, started his speech and explained each detail from the first moment as if it were his unconsciousness and passive knowledge coming to words. He did not remember any word when finished his speech, but it was fully sufficient and to the point. He felt as a feather and went to his seat while everyone was encouraging him. At the ceremony, the audiences were officially acknowledged about "Nader Health Card" issued by RADOIR to support the patients with medical services and its website: www.radoir.org for online registration. There was also a side event held by the active groups to serve the rare patients coinciding with the 1st edition of the international "Rare Disease Day". The event was quite welcomed by the official authorities as well as Medias. Now he felt relieved, RADOIR was established and still he had made the first step. There were two factors making him much more confident. One was God's grace and secondly, it was the people promised not to leave him alone to achieve his goals by all means of their heart.

Due to the fact that there was no special treatment for these types of diseases, he decided to focus all his efforts on the patients' prevention and recovery with the consultation of the experts and other RADOIR authorities. Considering that the rare diseases had no particular signs and symptoms which influenced the different organs of the body, he found it vital to ask doctors and specialists to join for the first medical group with the supervision of professor Kazemi Fathi, Dr. Motamed as Neurologist, Dr. Hossein Najmi as Psychologist, Dr. Hamid Reza Edraki as Radiologist in November 2010. About 150 patients were examined and their medical dossiers were filed. The tasks were turned to be much more executive professional in nature because of expertise doctors and specialists management. Passing by each room, you would hear the patient was confiding with a doctor who was listening by all means and senses, " I do not know whether it will be cured or not but if I would be aware what type of a disease I am suffering; then I would be happy. Fed up with referring to doctors and hospitals."



The reason why Ali had asked specialists with different expertise and skills to join him at the medical center was that he used to share their ideas, manners, experiences and applied them in the form of trials and errors through which he could manage different scientific subjects as a turning point for the rare patients. This was his policy. Professor Fathi was invited by RADOIR to supervise this section of the great work. He was the head of the International Society of the American Surgeons and at the same time, was managing the surgery board of several hospitals in Las Vegas. Also Prof. Fathi used to be the editor-in-chief of the International Surgeons Journal as well as the Academic Journal of Nerves and Bones of America. The best choice that Ali Davoudian could make was Prof. Fathi who got back to Iran after 50 years. He had 800 surgery articles and was the first to discover that shunts can be used to cure brain attacks. Besides he invented the famous drug and medication Skelaxin prescribed for diseases like MS to adjunct to physical therapy, accordingly. Professor was quite well known in medical worldwide. He was medium height, kind and full of love towards his mission while visiting the patients. He found out that Professor was very keen on having further trips to Iran and visit the patients for free, inspite of having long residence in abroad. He deeply tended to do surgeries in the Iranian hospitals. But it was a time consuming procedure with too much obstacles. Yes, it was not that much possible he regretted that the Iranian genius doctors with such mentality should be far from the patients craving for their medications. At that moment, he was proud indeed to provide such occasions that the patients could take the benefit of the doctors' welfare over there at RADOIR.

His awareness of the rare diseases was raised through socializing with the doctors at the foundation, checking the latest health care news about rare diseases with overseas online health press and sharing ideas and information with the referees and the foundation. Now the answers to his questions were popped up to his mind as he saw the kid for the first time; why he had not seen a patient like her before. It was one of the numerous types of the rare diseases with low prevalence per each. Some of these patients didn't tend to be appeared in the society. Imagine when someone has a headache and is not in a good mood, he or she doesn't like to talk to anyone, let alone they are suffering the difficulties with rare diseases and they cannot stand the looks and views on themselves and prefer to get on alone. Once one of the doctors explained him about the age of affliction to diseases, he believed that sometimes symptoms appear at birth or during childhood and some in the onset of puberty.

Although he knew that these types of diseases are not curable, he was looking for a way to stop its prevalence. The doctor told him that 80% of the diseases are caused by genetic disorders of which 75% children are exposed and afflicted and also 30% of them could not survive more than 5 years. Dr. Davoudian remembered the first day when he was planning to support the patients; a numb feeling came over him, as the foundation was established and he was doing his best for helping them. This foundation could become one of the biggest research organizations for supporting patients with Rare Diseases and in near future, a healthcare center could be



established at which well trained, skilled and expertise personnel serve rare patients in the peaceful environment.

One of the inherited Rare Diseases is Epidermolysis Bullosa (EB) that causes blisters and wounds on the skin and 1 out of 50 people are affected by that, it is worth saying that there is no superiority in getting affected by EB. The experts group of RADOIR foundation could identify 40 families suffering from this type of disease after 6 months. The foundation had been alone in providing rare patients with medical services, but sometimes he saw patients who came to receive healthcare services, share their experiences since they used to take care of their patients without any collaborator's assistance. So a simple scientific gathering would be so helpful at which all the patients and their families could join and receive special medical information and share their stories. The first meeting of EB patients was held at Rare Diseases Foundation of Iran on February 2010. The night before the gathering, he was really anxious and impatient. He didn't feel the same at his usual meetings. He understood those blisters and ulcers on kid's skin had made him standing where he was. He was stressful and also decisive to follow his way in supporting human beings in general, and he believed God is great and omnipotent. The remarkable point was the patients' families who managed the meeting without any intervention of the foundation and they talked about their status and choice of way to overcome the problems and obstacles as per expected, accordingly. During the event, he saw a seven-year old girl affected by EB. He passed people between the rows towards her. There was a smile in the depth of her sparkling eyes, he started to talk to her and asked about her favorites. He was trying to prevent himself from weeping not to make her sad. He held her hands and took a picture with her as a memento. Was so delighted that he could imagine the same feeling ever had.

It was a great pleasure to him to bring all the patients together and encouraged them to have more social activities and their families shared their stories and stop them from feeling alone. The meeting was going ahead spontaneously and he was satisfied with the mutual collaboration between rare patients and RADOIR authorities. "This event should be held each year." he thought.

The meeting was so rich in its concept and theme that it would be a necessity to continuously be held. The required actions and facilities for next edition could be defined and specified. The aim was to raise awareness about rare diseases, but he decided to bring a group of psychologists, dermatologists, pharmacists as well to visit the patients at the event, since EB was rooted in genetics, it could provide some genetic tests to those families who decide to have a child.

People at the gathering were informed about genetics and relevant diseases and Dr. Ebrahimi, professor assistant at Shahid Beheshti University of Medical Sciences, talked about genetic tests and also its profits for patients and their families. Dr. Marzieh Moazen Zadeh, professor assistant at Shahid Beheshti University of Medical Sciences, consulted patients and their families in this regard. Large numbers of participants were included with EB children and their families as the soul and spirit of



the event. Fortunately, EB could not take their joy and while they were able to get rid of the pain, you could see the shine in their eyes. They were bored by doctors' speech, it was easily understood since they were playing with the chairs and distracting the parents' attention. There were lots of toys to entertain all of them. The team had already guessed what would be going on during the event. The foundation couldn't provide all the facilities for the patients, so prepared some credit cards for them to be able to use the medical and clinical services free of charge. There are some patients who had recently been afflicted to EB and didn't know about the cards, Mr. Hamed Asghari explained the way they could use them.

Before the meeting he was thinking about the event. He looked at his hands whose had done lots of things; they were healthy with strong and powerful fingers. He remembered hands of the kid whom he had seen at Parsian Imaging center and put his hands image next to hers, asked himself," Is she able to play like others?" "Working at the foundation for a while, he could find out that they have difficulty to do their routines let alone playing. They could not eat ordinary and normal food and for putting on their clothes sometimes they had to wear bandage before. He thought of healthy children who could wear clothes carefree, swallow up anything, run and play without feeling any pain. But painful ulcers did not let the affected children to eat easily and they had to bear heavy burden on their shoulders.

The meeting was the best place to look for the cure or at least something to make tranquil their scars in a way. Daya Teb Co. training team started teaching the patients the best way to bandage them and gave them free coriander cream. The first meeting at the foundation was a good practice. The event had impressive media coverage. It also encouraged many families to refer to the foundation for medical services. More than 50 patients with EB received support, afterwards.

Documents and evidences proved that some of rare diseases were not domestic and were transferred into the country by the immigrants, thus the foundation decided to get more familiar with these types of diseases through joining the global references for the rare diseases.

Communicating with the European Rare Diseases Alliance (EURORDIS) and National Organization for Rare Diseases (NORD) got started. They provided the foundation with precious resources and data. Also two members from the European organization traveled to visit RADOIR. The foundation had been cooperating with them for long term. They had always admired his approaches in managing the foundation. The foundation was looking for different rare diseases all over the country, in addition to the news from other international organizations, there were also reports of patients received from various regions of the country. Last year, RADOIR members traveled to several different cities to identify rare patients.

In one of the trips, they found a child whose organs were damaged because of the disease. She was a young girl with brittle bones exposed to any malformation of the body. They had laid her on the bed. And Ali was trying to control himself, he couldn't be cool when he saw her suffering, it could not be possible. It was the most



painful scene he had ever faced in his lifetime. Her body was wrinkled and crumpled. He thought of her family and how could they stand the situation? Their patience and strength were admirable, indeed. He left the room shortly and he couldn't stand up on his feet anymore. When the others came out, they didn't see him. They thought he might be at the yard but he wasn't there. As if he had disappeared and did not answer his cellphone. So confused and he could not forget what he had seen. He couldn't stay there and drove his car to the road he knew well and he found himself by the holy shrine. There was tidy and very clean. He sat at the corner and stared at the shrine. He was really feeling pained and sickly so deep as if he were patient himself and suffering. Why did some people have to tolerate such this terrible condition? He got blurred in vision and fainted before getting his answer. His colleagues saw his car out of the holy shrine and they could find him while the emergency team was by his side.

When he got conscious, there was no time for giving up, these patients need somebody to take their hands and help them with their sufferings. He had not neglected them even for a single moment since he had established the foundation, never been doubtful about his intention and every day became more determined. Although there were lots of obstacles on his way like being ignored by The Ministry of Health, he did not become discouraged, for he was sure that it was his own responsibility and mission on the earth.

Seven more symposiums on Rare Diseases were held after the first and second one and all were as significant as the first event. At the event, the atlas of rare diseases of Iran was presented and introduced as well as RADOIR's annual report, indicating its objective to raise the public awareness about the rare diseases. The symposium was impressed by Dr. Hamid Reza Edraki's speech who was a holy defender and veteran of war and a member of RADOIR. He explained to the audiences more completed concepts and details about the rare diseases. This event was really great in result and has a successful media reflection. Lots of authorities were invited to each of the events and several artists and athletes participated as well. Some were selected as ambassadors for rare diseases. Several specialists, government authorities, representatives of scientific and academic institutions from all over the Europe joined the congress and got further familiar with Rare Diseases Foundation of Iran and its careers. Some patient's societies joined RADOIR to receive support and medical services.

"The little girl's missing skin was like the butterfly's thin and silk wings", he implied. Yes, the butterfly silk wings was the only description he could leave on the scene with which he faced for the first time at the Imaging center. Now his little butterfly fairy was calling him grandfather and said: "Love you grandpa!" He was on the ninth cloud when she called him and felt wonderfully happy since he had become an advocate for the patients.

Through his deep thoughts, he felt afraid of grandeur and magnitude of the responsibility he was in charge. How could he manage all those activities alone? He



prayed for God in his privacy and through his supplications, he asked," God! Where are you taking me? " Remembering his start up at childhood, he was thinking how a little lonely boy could identify rare patients and include their records in healthcare system of the whole country and make everyone astonished. Now he found that it was possible.

The grandfather was called for a heavenly mission by the omnipotent God. He was invited to serve the patients with the heavenly mercies and blessings while he, himself was a guest called by the beneficent God for his everlasting trip which has no end and still goes on. Dr. Ali Davoudian had found a gentle and better path to the end of his life and his endless journey had begun. But in the meantime he flied with many little butterflies beyond imagining and upon the wind of heaven's love despite holding bittersweet memories and hoping for peace forevermore.



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