

LOK SABHA DEBATES

LOK SABHA

Tuesday, March 12, 1996 / Phalgun 22, 1917 (Saka)

The Lok Sabha met at Eleven of the Clock

[MR. SPEAKER in the Chair]

ORAL ANSWERS TO QUESTIONS

[Translation]

Thalassemia Disease

*162. DR. RAMKRISHNA KUSMARIA :

SHRI PANKAJ CHOWDHARY :

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state :

(a) whether the Union Government have formulated any comprehensive scheme for the cure of Thalassemia disease;

(b) if so, the details thereof;

(c) the number of Thalassemia patients in the country at present; and

(d) the number of Government hospitals in the country where the facility for the treatment of this disease is available at present?

[English]

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (DEPARTMENT OF INDIAN SYSTEMS OF MEDICINE AND HOMEOPATHY) SH. PABAN SINGH GHATOWAR) : (a) to (d). The only curative treatment for Thalassemia requires bone marrow transplantation which is an extremely complex procedure, requiring an identical sibling donor. However, research in Thalassaemia is a major thrust area for the Indian Council of Medical Research (ICMR). They are supporting extramural research at the Christian Medical College Hospital, Vellore, which is being developed as a referral centre for bone marrow transplantation. Thalassaemia patients are currently subjected to repeated blood transfusions as a life saving measure.

No reliable estimate is available of the Thalassemia patients in the country.

[Translation]

DR. RAMKRISHNA KUSMARIA: Mr. Speaker, Sir, the reply of the hon. Minister to this question clearly proves that the innocent children suffering from Thalassaemia

disease live a painful life due to deficiency of haemoglobin in their blood. They are subjected to repeated blood transfusions every third or fourth week in order to meet this deficiency of haemoglobin. But in his reply, the hon. Minister has not been serious enough to state whether any effective treatment has been devised for the disease that has afflicted lakhs of children. He did not even refer to a recent two day Conference of the scientists of Institute of Ayurveda in which a reference was made to a recently developed medicine namely Dephrifone tablet that is capable of relieving the children of this pain, of taken orally.

Through this question, I would like to ask the hon. Minister whether this Dephrifone tablet developed in India...*(Interruptions)*

MR. SPEAKER: You should not ask such questions. Please do not ask this. Come to another question.

(Interruptions)

[English]

MR. SPEAKER : Otherwise you appear to be pleading for some medicine

(Interruptions)

[Translation]

MR. SPEAKER : No, please set that question aside. Come to the other question now.

RAMKRISHNA KUSMARIA: For its treatment, our Government and the hon. Minister...*(Interruptions)*

MR. SPEAKER : Some other new drugs are being tested. Will you take into account those also?

DR. RAMKRISHNA KUSMARIA: I would like to know whether research is being conducted by the Government on a new treatment or medicine for this disease?

[English]

SHRI PABAN SINGH GHATOWAR : Sir, I have already stated that thalassemia is one of the complex diseases. It is prevalent all over the world. As of today, bone marrow transplantation is the only treatment and there is another where the patient has to go in for a change of his blood. That also is a very painful process. These are the only two proven methods of treating thalassemia. A research is going on but it is not in the conclusive stage.

[Translation]

DR. RAMKRISHNA KUSMARIA : Will the hon. Minister

formulate a scheme envisaging a serious research on it by bringing it under the purview of National Health Policy?

[English]

SHRI PABAN SINGH GHATOWAR : Sir, we have taken it up with all seriousness and we have given a project to the Christian Medical College, Vellore, where the research is going on and all support is given by our Indian Council of Medical Research, for the research.

[Translation]

SHRI PANKAJ CHOWDHARY : A regular monthly blood transfusion is a must for a patient of thalassaemia and hundreds of lives are lost due to non-availability of blood in the country. What necessary measures has the hon. Minister taken to ensure availability of blood?

[English]

SHRI PABAN SINGH GHATOWAR: Sir, I have already stated in this august House before also that blood cannot be purchased, it has to be arranged by some donor and the patient has to arrange the donor for the blood. Then, they can transfuse the blood in various hospitals in our country. But it is the responsibility of the family of the patient to arrange for blood because blood cannot be purchased anywhere.

KUMARI MAMATA BANERJEE : Sir, actually, this thalassaemia is a disease where there is no concrete step taken so far. Two things are needed for the thalassaemia patients; one is blood and the other is the desperate injection. You will be surprised to know the price of the medicine. They cost sky high. For the thalassaemia patients, they have to give two injections, at least, in a month. When I was a Minister, I pursued this matter when the price of the injection was Rs. 360. Then, the Minister kindly considered it and it came down to about Rs. 200, but it has now again gone up to more than Rs. 400.

As for blood, the middle class and the other people are able to donate blood. So, there is no problem for getting blood, but the problem is for the injection. Will the Minister consider the price of the desperate injection for the thalassaemia patients? Will the Minister reconsider to decrease the price? Otherwise, it is not possible for the poor people to continue with the treatment.

My next point is this. It is a serious matter. So far, we know we have blood banks in our country. The thalassaemia patients do not get any relief from the Prime Minister's Relief Fund or the Chief Ministers' Relief Fund. They do not have the scope for that. So, will the Minister open a thalassaemia bank, so that the poor people can get assistance from that bank?

SHRI PABAN SINGH GHATOWAR : Sir, I am quite in agreement with the concern of the hon. Member for the thalassaemia patients. As far as I know, I have already said that there are only two types of proven treatment, that

is the bone marrow transplantation and the blood transfusion. There are some medicines too. (Interruptions)

KUMARI MAMATA BANERJEE : What about that particular injection? They need two injections in a month.

SHRI PABAN SINGH GHATOWAR : Sir, I do not have the details with me.

MR. SPEAKER : It is a technical matter. You can give that later.

KUMARI MAMATA BANERJEE : Sir, they can reconsider the price.

MR. SPEAKER : If that kind of a medicine is expensive, will you consider giving some help, some subsidy, some assistance? Please examine it.

SHRI PABAN SINGH GHATOWAR : There is a fund available which is at the disposal of the Cabinet Minister of Health and definitely we will try to consider giving assistance to the poor thalassaemia patients.

[Translation]

SHRI DAU DAYAL JOSHI : Mr. Speaker, sir, the hon. Minister has not furnished any information in reply to the first part of the question. He said that these figures are not available with him. According to a survey, there are more than one lakh thalassaemia patients in India. At present its treatment is available only under the Allopathic System of Medicines which is very costly. On the basis of allopathic treatment, the patient is left with a mere two percent survival expectancy even after spending one lakh. 98 percent patients including children fall a prey to death. My question is that when it has been established that allopathy does not cater fully to its treatment, will the hon. Minister, who has recently taken charge of the portfolio of Ayurveda, take measures for checking thalassaemia disease by providing adequate funds for Ayurvedic research? If so, the time by which such measures will be taken?

SHRI PABAN SINGH GHATOWAR : Thank you for your valuable suggestion. We will make efforts in the direction of evolving its Ayurvedic or Unani treatment. We will hold consultation with our Research Council in this regard.

SHRI MOHAMMAD YUNUS SALEEM : Mr. Speaker, sir, with regard to the question raised by my friend, I have to submit that different Indian newspapers and journals came out with the articles some days ago revealing that no successful treatment in allopathy is available for many diseases, particularly those related to cancer. Instead, Ayurvedic and Unani systems of medicine can cater to such treatments but the problem lies in the non-availability of research facilities in the laboratories of Ayurvedic and Unani systems. Nevertheless, the modern strides in science have rendered the antiquated field of science of Ayurveda and Unani inadequate for the successful treatment of

such diseases. I would like to ask the hon. Minister whether he would formulate any scheme for providing funds to Unani laboratories set up for treatment of diseases through Unani system of medicines? Secondly, Homoeopathic system of medicines is becoming popular today. Kumari Mamata Banerjee has just now said that despite being a costly treatment beyond the reach of the poor, allopathy accounts for only two percent success-rate. The homoeopathic doctors claim that they can provide a cheap treatment to many patients outside the purview of allopathy. Will any attention be paid to conduct research in Homoeopathy?

[English]

SHRI PABAN SINGH GHATOWAR : Sir, the hon. Member knows that, with this purpose in view the Prime Minister has created a separate Department for Indian Systems of Medicine and Homoeopathy. Sir, we have three research councils, one each for Unani, Ayurvedic and Homoeopathy. Very recently our hon. Minister has laid the foundation stone for National Institute of Unani.

We are giving all support and encouragement to the three systems of medicines so that they can have a good research and give good results by which the population of our country will be benefited. All sorts of supports is there. There are claims, but those claims have to be counter-checked and scientifically proved and then only, we can say that this is the treatment for this disease. We have to go like that....(Interruptions)

[Translation]

SHRI MOHAMMAD YUNUS SALEEM : Mr. Speaker, sir, the complaint is, as revealed by the press also, that funds are not being provided to them. I want a specific reply as to whether adequate funds will be provided for research in Ayurvedic and Unani system of medicine? Why are not Indian systems of medicine being adequately funded in comparison to Allopathic system. He has not given any reply with regard to funds.

[English]

SHRI PABAN SINGH GHATOWAR : From our side, I have said that last year only, we have created a separate Department. We are providing a separate Budget for this Department; earlier it was a part of the Allopathic Department. Now, we have a full fledged Secretary; hon. Prime Minister has given me the charge of looking after the Department of Indian Systems of Medicine; and we have already proposed to the Planning Commission and we are trying to have more money. Definitely we are going to give them full support in this type of research....(Interruptions)

There will be no difficulty for this Research Council to have this type of a positive result.

[Translation]

SHRI HARI KISHORE SINGH : How much money you are ready to pay. Hon. Minister will say something about it, he will help us. All the people are agree. Mohammad Yunus and Mamtaji also agree on this point...(Interruption)

[English]

MR. SPEAKER : Only Shrimati Malini's question will be replied to.

...(Interruptions)

MR. SPEAKER : I will allow you later and not now. I have called Shrimati Maliniji. I will allow you later. Now, Shrimati Maliniji please.

...(Interruptions)

[Translation]

SHRI DAU DAYAL JOSHI : Mr. Speaker, Sir, if Government provide funds...(Interruptions)*

[English]

MR. SPEAKER : Nothing is going on record.

SHRIMATI MALINI BHATTACHARYA : The desperel injection which is required for bringing down iron deposits in the blood of the Thalassemia patients after its transfusion, is very very costly. I agree with the other Members that it should be provided either free of cost or at a low cost for Thalassemia patients at Government hospitals.

However, my question is different. We find that in certain countries where Thalassemia patients are abundant, they took up a programme by which it was possible for them to eradicate Thalassemia. That is, they made the blood test of couples who are about to get married compulsory, for possibility of Thalassemia. Now, I would like to know from the hon. Minister, whether the Government would take steps for making such blood tests compulsory so that eventually Thalassemia can be eradicated from the country.

SHRI PABAN SINGH GHATOWAR : About the injection, it was costly because there was a high customs duty...(Interruptions)

SHRIMATI MALINI BHATTACHARYA : Even now it is very costly....(Interruptions)

SHRI PABAN SINGH GHATOWAR : Now, the Government of India has taken it up and customs duty is free for that injection...(Interruptions)

SHRIMATI MALINI BHATTACHARYA : It is because there is no control....(Interruptions)

SHRI NIRMAL KANTI CHATTERJEE : In the course of the last three years, the prices have risen...*(Interruptions)*

MR. SPEAKER : You will reply only to the question of Shrimati Maliniji...*(Interruptions)*

SHRI PABAN SINGH GHATOWAR : There are only three countries, as the hon. Member has mentioned, which have taken up the national programme; and they are: Sicily, Cyprus and Italy. They have the pre-natal diagnosis of the mother, to check whether there is any Thalassaemia in her blood; and then call the father also to have the blood test done. If it is found positive, then they advise them to go for abortion and other things. This type of a thing is there only in those three countries, that is, Sicily, Cyprus and Italy which have taken it up. We are considering...*(Interruptions)*

SHRIMATI MALINI BHATTACHARYA : I am not talking of the pre-natal programme. I am talking of doing something before the marriage...*(Interruptions)*

MR. SPEAKER : Shrimati Maliniji, please do not do it that way. Let him complete please.

SHRI PABAN SINGH GHATOWAR : It is true that, as of today, it is not possible, with the given facilities to test the blood of each and every citizen of our country.

There is a recent judgement of the Supreme Court to upgrade and enlarge the blood bank and the blood testing facility in the country; Government is formulating a policy and is also trying to upgrade the blood testing facility at the State and Central levels.

[Translation]

DR. LAXMINARAYAN PANDEYA : Mr. Speaker, Sir, I want to know from hon. Minister through you that thalassaemia is such a horrible disease that it could not be controlled even now. Thousands of children fall prey to this disease every year. About 90 percent children die of this disease only 10 percent children could be saved from this ailment. Just as hon. Minister has said that he is considering to set up some more blood banks in view of the directive given by the Supreme Court, I think that if the number of blood banks is considerably increased and the treatment facilities are being provided as positive directions then we can almost have a control over this disease, otherwise there is every possibility of breaking out of any other disease out of it. As not only reported earlier, this disease attacks children but also adults, even adults have died of this disease. I want to say that some remedial measures should be taken to check its spread out by evolving a national outlook. As you have said that you are formulating some scheme for this, then when this scheme is likely to be formulated? What steps do you propose to take to implement that scheme in the big cities of the country with a view to control this disease.

[English]

THE MINISTER OF HEALTH AND FAMILY WELFARE AND MINISTER OF WATER RESOURCES (SHRI A.R. ANTULAY) : Hon. Speaker, Sir, actually this is one of those deadly diseases for which so far, inspite of every effort of research, no cure has been found. It is a matter of great concern and the Government is greatly exercised about it. It is true that there are tests which can be conducted, as the hon. lady Member and Mamataji have said but first of all, it will not be possible in a big country like ours to find out how many persons or couples are going to get married so that tests can be carried out. Let us hope that the day will come when it will be possible because that is the only way whereby we can do it. But more emphasis should be laid, as it has been suggested rightly according to me and the Government, on Indian system of medicines since allopathy has failed. Allopathy has failed in many respects. It has so far failed inspite of huge expenditure that has been booked for research and cancer; it has so far failed on AIDS and on this also. Therefore, of late, when allopathy has failed, we have been emphasising that the Indian system of medicine should step in and I have been making a public declaration all over that rather than man-made laboratory, remedy can be in the God-made laboratory, that is, the forest. The malady is created later but the remedy is created by God earlier. We are only to find where it is. I have said this all over and I have been emphasising that herbs are medicinally researched even in America today for cure of cancer and I may inform this august House that I had been to Chicago a few months ago and I was told by the doctors there that herbal research is being made and it is in the range of probability, and not possibility, that a cure for cancer can be found through that. So, if they can take herbs from us and make research there, why should we not do it ourselves? That is why, all through, I have been emphasising as also my colleague and officers who man this particular wing of this Ministry, on the Indian system of medicine or homeopathy and that we have got to give more funds to it.

KUMARI MAMATA BANERJEE : How about for injections, Sir?

SHRI A. R. ANTULAY : We have to give more funds to make research because whether we give injection or transfusion of blood or even marrow transplantation, it is not easy. Marrow transplanation is totally out of question as it is rightly said. Blood transfusion is also not that easy, it is very painful and difficult. We may lower the price, we may think of giving treatment free to the poor, but it is not only the poor who get this disease, even the rich people's children get this particular disease. So, we are actually exercised and we have been trying to do everything, right from the research to the cure and to the end, that is, remedy. Therefore, I think, we are at the moment...

SHRIMATI MALINI BHATTACHARYA : It can be given at a low cost in the Government hospitals, that is the suggestion.

SHRI A. R. ANTULAY : What I said was - I think, the hon. lady Member has heard me - that so far as the patients who are poor or poor parents' children are concerned, we certainly shall see that they are given treatment at an affordable cost, if not totally free, which will be as far as possible, 'free'. This disease is prevalent not only among the poor, but among others also. For those who can afford, certainly, we cannot give treatment like that; we can make the facility available for them, but we cannot make the treatment free. That is the best at the moment that the Government can do and what the Government intends to do, that also I have said on behalf of the Government.

SHRI RAMESH CHENNITHALA : In the answer, the hon. Minister has mentioned that no reliable estimate is available about the Thalassaemia patients in the country. I think that this is a very dangerous disease and the Government of India should collect the data and a definite estimate about this; and the Government of India should reliably estimate as to how many patients are suffering by this so that they can be given proper financial help.

Secondly, in Kerala, in Kottayam and Alleppey districts, there is a very dangerous disease which is similar to Thalassaemia. We cannot say that this is the same disease which is spreading; and more than 50 people died recently because of this. I would like to know from the hon. Minister, whether the Union Government is aware of this and whether the Government of India will send a team of doctors to identify the disease and give proper assistance to the State Government to eradicate this disease.

SHRI PABAN SINGH GHATOWAR : Thalassaemia is the commonest of the hereditary diseases and it can be found out only after examining the blood of the patients. Examining the blood of the patients, as I have already stated, is very difficult, but still we, in the Government, will definitely take note of the suggestion of the hon. Members who have expressed concern.

About the Kerala's case, I have no information and definitely, I will look into it.

DR. MUMTAZ ANSARI : Mr. Speaker, Sir, as it has been just now brought to the notice of the august House, more than one lakh patients are suffering from Thalassaemia disease across the nation; and the people affected are not only from the city areas, but also from the rural areas. But the blood transfusion centres and the marrow transplantation centres are located in big cities. That is why, I would like to know from the hon. Minister, whether there is any provision or proposal to set up such blood transfusion facilities and the marrow transplantation facilities also in the Government hospitals in the rural areas so that the rural patients may take benefit out of that; and how much cost is going to be subsidised for that and to what extent the poor patients will be helped by the Government of India.

SHRI PABAN SINGH GHATOWAR : I have already stated that the marrow transplantation is a very very complex one and it is very difficult. As of today, we have successful marrow transplantation centre only in the Christian Medical College, Vellore and nowhere else it is available. We have marrow transplantation in the All India Institute of Medical Sciences for Leukaemia and in two other Institutions. But marrow transplantation is successfully done only in the Christian Medical College in Vellore. So, it will not be possible to provide it in every State. But definitely we will try to have it in more Centres. Definitely, it is a very complex one.

SHRI AMAL DATTA : It has already been stated that only a year ago the Government of India has started paying substantial attention to the indigenous systems of medicines.

Sir, I may say that more than a year ago, much more than a year ago, a Report has been submitted by the Government to the Parliament regarding rules of the Medical Council of India which says that it does not inculcate any knowledge in the students of modern medicine about what is possible, what are the kinds of cure in the indigenous system. It has been stated in the Report that some modicum of knowledge should be given to the students coming out with MBBS degrees so that they could direct patients coming to them for which there is no cure in their own system of medicines to the other systems of medicines.

Unfortunately, they have not taken any appropriate step. They have been taking time again and again. I would like to know, what steps have been taken by the Government upto now. The report was laid on the Table of this House in December, 1994 but nothing has been done yet. Have the Government taken steps to change the MBBS course so that students passing out with MBBS degrees in modern medicines are also knows something about the other systems of medicine so that they could direct the patients to those alternative systems which are available at much lower cost to them.

SHRI A.R. ANTULAY : Basically, I am speaking subject to correction, I feel that it is better - as I said here sometime ago - to have all the systems under the roof so that if patients could not be cured by one system, that is Allopathy, they could have access to other forms of medicines like the Homeopathy, Ayurved and Unani. But somehow in principle, it does not go home with a person like me that there should be a grafting of the two or three systems - Allopathy-cum-Ayurved-cum-Homoeopathy.

Now, the course for the MBBS is allopathic. It has been suggested by the hon. Member that there should be some modicum for other systems of medicines also in ICMR. But that research should be done separately. I am not against the research of Unani and Ayurved in ICMR. In fact, we have already instructed them that they should carry on the research in these fields of medicines also.

But that should be done side by side and not mixed together. Therefore, the suggestion of the hon. Member is well taken. We shall issue more instructions to them in this regard. In fact, I shall request the DG, to carry on the research in Ayurved and other systems of medicines separately in ICMR.

SHRI AMAL DATTA : What about the education?

SHRI A.R. ANTULAY : Sir, so far as education is concerned, I am afraid, my view is that after passing the MBBS course it is no good to give education to these students on Ayurved or Homoeopathy. That would be a mixture. One would not know about it and one has to go into research to find it out. According to me, either we have to develop Ayurved, which we have not done so far, or we have to develop any other form of medicine. But you cannot say that 50 per cent or 35 per cent of Ayurved, 60 per cent of Homoeopathy - that sort of a thing, according to me, would not be good.

SHRI AMAL DATTA : Why do you not consider and give a reply? Patients who goes to a doctor of modern medicine he/she would not advice the patient to go in for Ayurved system of medicine unless he/she knows something about that system.

SHRI A.R. ANTULAY : Through the hon. Speaker I would like to submit that we want to achieve that aim. There is no question of one being on this side or that side. We want the disease to be eradicated. It depends upon the perception. The perception of the Government is, the part of the recommendation which is feasible would be accepted and the part of the recommendation which according to the Government is not feasible would not be accepted. That is the thing which I have said.

[Translation]

SHRI UPENDRA NATH VERMA : Mr. Speaker, Allopathic, Ayurvedic and Homeopathic systems of medicine have been talked about in regard to the Treatment of 'Thalassemia' I want to know from the Government as to whether the Government has made efforts to solicit informations from the 'Nature cure' or 'naturopathy' specialists.

[English]

SHRI PABAN SINGH GHATOWAR : Sir, I have already stated that we have been encouraging all the systems of

medicines. It is a good suggestion from the hon. Member.

[Translation]

SHRI UPENDRA NATH VERMA : It has also been witnessed that the disease for which there was no cure in Allopathy, Ayurved and Homeopathy has been very much cured by Nature cure. Therefore, we should put emphasis on Naturopathy also for curing the disease like 'Thalassemia'.

National River Conservation Plan

*163. **DR. SATYANARAYAN JATIYA :**

SHRI HARI KISHORE SINGH :

Will the Minister of ENVIRONMENT AND FORESTS be pleased to refer to the reply given to Unstarred Question No. 383 on August 1, 1995 and state:

(a) whether the proposed National River Conservation Plan (NRCP) has been taken up;

(b) if so, the details thereof and the percentage of work implemented under the Plan, so far;

(c) if not, the reasons therefor; and

(d) the time by which it is likely to be commenced?

THE MINISTER OF STATE OF THE MINISTRY OF ENVIRONMENT AND FORESTS (SHRI RAJESH PILOT) : (a) to (d) Yes, Sir. The National River Conservation Plan has already commenced. Prefeasibility Reports for pollution abatement works in various towns (except for towns in Rajasthan) were approved in August, 1995 & the State Governments were asked to prepare Detailed Project Reports for individual schemes and submit the same for sanction. Funds for preparation of the Detailed Project Reports were also released to the State Governments.

The State Governments have recently submitted a few Detailed Project Reports while the remaining Detailed Project Reports are in preparation stage. The Status of approval of Detailed Project Reports and the funds released to various State Governments till date is given in the statement laid on the Table of the House. The State Governments have initiated formalities for award of work for actual implementation of the approved schemes and works under these schemes are likely to start shortly.