

GOVERNMENT OF INDIA
MINISTRY OF FINANCE
DEPARTMENT OF REVENUE

LOK SABHA
UNSTARRED QUESTION NO. 85
TO BE ANSWERED ON MONDAY THE 29TH November, 2021
AGRAHAYANA 8, 1943

Waiver of GST

85. SHRI A.K.P. CHINRAJ:

Will the Minister of FINANCE be pleased to state:

- (a) whether it is a fact that based on a VIP reference, the waiver of Goods and Services Tax (GST) for drug Zolgensma was approved for a child from Tamil Nadu;
- (b) if so, the details thereof along with the VIP reference on which it was approved; and
- (c) the date on which and by whom the first VIP reference was received in this regard?

ANSWER
MINISTER OF STATE FOR FINANCE
(SHRI PANKAJ CHAUDHARY)

- a. Several references were received for the waiver of applicable Integrated Goods and Services Tax (IGST) at the time of import of drug Zolgensma for a child by the name of Baby K.S. Mithra from Tamil Nadu. In addition to the references, the request was also received from the father of the baby K S Mithra, Shri Satheesh Kumar vide email dated 08.07.2021. The case was examined on merits and waiver was granted vide *Ad hoc* Exemption Order no 09/2021 dated 14th July 2021.
- b. A copy of the *Ad hoc* Exemption Order is enclosed along with the related references and request received vide mail dated 08.07.2021 from the father of the baby K S Mithra, for the subject case.
- c. The First reference in this regard was received in this Ministry on 6th July 2021, through an email communication from the Department of Commerce.

Enclosures: As above

F. No. 461/11/2021-Cus V
Ad-hoc Exemption Order no. 9 of 2021
Issued under section 25(2) of the Customs Act, 1962

Government of India
Ministry of Finance
Department of Revenue

Room no. 227A, North Block, New Delhi – 110001

Dated the 14th July, 2021

To,
The Chief Commissioner of Customs,
Bengaluru Zone
Bengaluru

Sir,

Subject: Request for Special Exemption from payment of Customs Duty under Section 25 (2) of Customs Act, 1962 on import of Zolgensma– reg.

The undersigned is directed to refer to a request received from Mr. Satheesh Kumar, father of baby K.S. Mithrra, seeking exemption from payment of duty in terms of Section 25 (2) of Customs Act, 1962, for import of Zolgensma, a drug for gene replacement therapy.

2. He has informed that:

- (i) his daughter, K.S. Mithrra, has been diagnosed with Spinal Muscular Atrophy, type 1, a severe, rare, early-onset genetic disorder that affects a child's nervous system and eventually kills the baby as the condition progresses.
- (ii) they have raised money (INR 16 crores) to cover costs for a revolutionary gene replacement therapy, Zolgensma, priced at USD \$2.125 million, to save his life, through crowd funding.
- (iii) they have obtained approval from DGCI to import this life saving medicine for personal use.
- (iv) the drug Zolgensma needs to be imported from USA and as per the doctor's advice and the infant's weight, 55 ml of the drug would be required for the treatment.
- (v) The drug is expected to be imported as 1 package with 55 ml doses of medicine.

2.1 They have requested for waiving off the customs duties and GST on the import of this lifesaving drug Zolgensma.

3. In view of the exceptional circumstances as mentioned above, the Central Government in exercise of the powers conferred by sub-section (2) of Section 25 of the Customs Act, 1962 (52 of 1962), being satisfied that it is necessary in the public interest so to do, hereby exempts 55 ml of Zolgensma, from the whole of the Integrated Tax leviable thereon under sub-section (7) of section 3 of the Customs Tariff Act, 1975, subject to the condition that the imported goods will be used for the treatment of Baby K.S. Mithrra and will not be put to other use. The said drug is already exempt from payment of BCD under Sl. No. 607 of Notification 50/2017- Customs dated 30th June, 2017, subject to conditions therein.

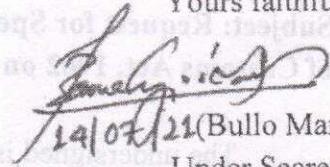
F. No. 461/11/2021-Cus V
Ad-hoc Exemption Order no. 9 of 2021
Issued under section 25(2) of the Customs Act, 1962

4. An undertaking that the goods covered by this Order will be used solely for the treatment of Baby K.S. Mithra and shall not be put to any other use shall be submitted by the applicant to the jurisdictional Commissioner of Customs of the port of import for claiming benefit of exemption under this Order.

5. Any infringement of conditions of this Order should be brought to the notice of the Commissioner of Customs of the port of import for taking further necessary action such as realization of Customs duty on the subject goods, penal action for such violations, etc.

6. This order is valid for imports made up to 13.10.2021

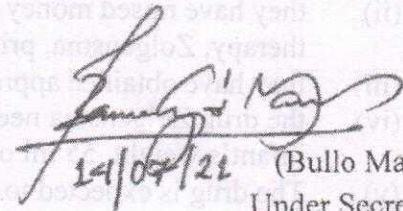
Yours faithfully,


14/07/21

(Bullo Mamu)
Under Secretary

Copy to:

- Mr. K. Satheeshkumar 5/68-23, Thirukumaran Street, Gandhinagar, Komarapalayam, Namakkal, Tamil Nadu- 638183.
- Principal Director (Customs), Central Receipt Audit Wing, Office of the Comptroller & Auditor General, 10, Bahadur Shah Zafar Marg, New Delhi-110 002.
- Guard File.


14/07/21

(Bullo Mamu)
Under Secretary

A.K.P. CHINRAJ, B.Sc.
MEMBER OF PARLIAMENT
(LOK SABHA)

Namakkal Constituency - Tamil Nadu

MEMBER:

- Standing Committee on Rural Development
- Consultative Committee on the Ministry of Housing and Urban Affairs



सत्यमेव जयते

32, Meena Bagh, Opp. Vigyan Bhavan,
Maulana Azad Road, New Delhi-110011

No.2/192, Kallaiyan Kedu,
Alampatti, Rasipuram Taluk,
Namakkal-637 505, Tamil Nadu
Mob.: 94432 32190, 92445 32190
E-mail : akpchinraj190@gmail.com

Received Today
विधि अनुमति के मांगे मंडल/वि
Personal Section, D. G. F. T.
डा. सं/Dy. No. YIP-152845
दिनांक 28/06/2021

21.06.2021

To

Hon'ble Shri Piyush Goyal Ji
Minister for Commerce and Industry
New-Delhi.

वाणिज्य एवं उद्योग मंत्री कार्यालय
C&I M's Office
दफ्तरी नं. / Dy. No. YIP-3794
दिनांक / Date 25/06/2021

Sub-Relaxation Import GST for drug ZOLGENSIA

Hon'ble Sir,

Vanakkam, It was brought to my notice, that a child from my constituency suffering from a rare genetic dis-order, there is immediate demand of drug Zolgensia which cost around 16 crore which is exclusive of six crore rupees as Import GST, in this regard I have enclosed the details of the patient, I request by discretionary power exempt it from GST, and save the life of child.

Thanking you

Yours



Member of the Standing Committee on rural Development
Consultative committee on the Ministry of Housing and Urban Affairs

The relevant details attached herewith.

ADGFT (AS)

28/06/2021

Handwritten notes and signatures at the bottom of the page, including "JOC (F&A) in table up to date" and other illegible signatures and dates.



Mrs. Vanathi Srinivasan
 MLA, Koval South, Tamilnadu
 National President - Mahila Morcha
 Bharatiya Janata Party

Date : 28.06.2021

Shri. Narendra Modi,
 Hon'ble Prime Minister,
 Government of India

Sub : Waiver of Import Duty and GST on Life Saving Medicine and request for assistance under PMNRF reg...

Respected Sir,

I bring to your notice, the plight of Baby. S.Mithra (Aged 23 months) d/o Mr. K. Sathish Kumar residing at 5/68-23 Thirukumaran Street, Gandhi nagar, Kumarapalayam (PO), Namakkal - 638183, Tamilnadu who is suffering from Spinal Muscular Atrophy.

The baby is in immediate need of the drug Zolgensma, which is to be imported from the United States to save her life. This is the same drug that was imported for Baby. Zaha Zameh in the month of March 2021.

The parents Mr. K.Sathish Kumar and Mrs. Priyadharshini are unable to afford the high cost of the drug, which costs close to Rs.16 Crores and have resorted to crowdfunding to save the life of their Daughter.

I requested you to waive the Import duty and GST on this life saving medicine, which amounts to 35% of the cost of medicine and to grant them assistance under PMNRF to help the baby to get the medicine as early as possible.

Thanking you

Copy to :

1. Smt.Nirmala Sitharaman,
 Hon'ble Minister of Finance
2. Dr. Harshavardhan,
 Hon'ble Minister of Health and Family Welfare

Yours,

Vanathi Srinivasan
 Vanathi Srinivasan

Email

fmo

Regarding- One time waiver of GST and Import Duty for ZOLGESMA medicine for a 2 year old baby K.S.MITHRRA

From : Kanimozhi Karunanidhi <kanimozhi@sansad.nic.in>

Mon, Jul 12, 2021 06:54 PM

Subject : Regarding- One time waiver of GST and Import Duty for ZOLGESMA medicine for a 2 year old baby K.S.MITHRRA

5 attachments

To : fmo <fmo@nic.in>, appointment fm <appointment.fm@gov.in>

1749485
FM/VIP/2021

12-07-2021

To,

Ms. Nirmala Sitharaman
Hon'ble Minister for Finance,
Government of India,
New Delhi

RS in Meeting

Respected Ma'am,

This is to request you for a one time waiver of import duty and GST for the medicine ZOLGENSMA which is to be used for treating a two year old baby K.S.Mithrara D/o Mr. K. Satheesh Kumar. The baby has been suffering from Spinal Muscular Atrophy(SMA), a genetic disorder since birth and her condition is deteriorating day by day. The parents have managed to raise 16 crore rupees through crowd funding to buy the medicine ZOLGENSMA and the import duty costs an additional 6 crore rupees. In view of the above circumstances and the medical condition of the baby, I request you to waive the import duty and GST for this medicine to enable the baby to take the treatment immediately. The medical reports and the identity proofs of the baby are attached herewith.

14
PST
AS

Thank you.

Sincerely,
Kanimozhi Karunanidhi

Comm (Gen)

15-7-21
Shri Rajesh

15/07/2021

Attachments:

- 1. Medical Certificates from Bangalore Baptist Hospital

A. GANESHAMURTHI

MEMBER OF PARLIAMENT
LOK SABHA
ERODE - TAMIL NADU



सत्यमेव जयते

22, Dr. Rajendra Prasad Road,
New Delhi - 110 001

H-45, Periyar Nagar, ERODE-638001 (T.N.)
Tel.: 0424-2240099, 2256713
Mobile : 09442516162

Member :

- Standing Committee on Agriculture
- Consultative Committee on Electronics and Information Technology

12.07.2021

1756100
20 JUL 2021
FM/VIP/2021

Thirumathi Nirmala Sitharaman Avl., Vanakkam.

Subject; Waiver of Import Duty & GST to import 'ZOGENSMA' medicine.

I am duty bound to forward an appeal received from Shri K. Satheeshkumar, father of Baby K.S. Mithrra , aged 23 months only, who is unfortunately affected by SPINAL MUSCULAR ATROPY decease since birth.

This poor family lives in my constituency namely Komarapalayam of Namakkal District and they have approached me for help. On hearing the apathy of this case, I have personally visited them and offered to help them in mitigating their financial problems connected to this issue.

The Doctors attending on her have finally confirmed that the medicine name as 'ZOGENSMA' needs to be imported from USA and Shri Satheeshkumar is putting in his best efforts to secure the amount required. Many have come forward to help this noble cause.

The import duty for this stands at 23% and the GST on its is 12%. Thus the duty and GST comes to nearly Rs. 3 crores. The unfortunate father of the patient is not wealthy enough to meet this cost. I am convinced of his liability. Therefore, by forwarding his application which is enclosed. I strongly recommend that Shri Satheeshkumar may kindly be permitted to import this medicine without import duty and GST payable to our nation.

Incidentally, I also understand that a similar appeal from a patient from Hyderabad has been sympathetically considered by your good office. I highly appreciate the fine gesture.

Therefore, I request you to consider the application of Shri Satheeshkumar with utmost sympathy and permit them waiver of import duty and GST on the medicine to be imported to cure the sickness of Baby K.S. Mithrra.

With regards,

Somnath
for n.a.

our related (DS(45))

Yours,

(A.GANESHAMURTHI)
12.7.2021
(A.GANESHAMURTHI)
IC No. 362.

Thirumathi Nirmala Sitharaman
Hon'ble Minister of Finance,
Government of India, New Delhi.

Vu
26.7.21

DSD(45)

Chiranjeev

23/07/21

19/x
PS to FM
CH(10)
M(TP)
JSLTRU
DS(45)

DR. S. SENTHIL KUMAR, MDRU
Member of Parliament
(Lok Sabha)
Dharmapuri Constituency - Tamil Nadu



सत्यमेव जयते

Vaigai Iliam, Old Tamil Nadu House,
No.6 Kautilya Marg, Chanakyapuri,
New Delhi - 110 021

No.12/9-C,
Winding Driver Chinnasamy Street,
Dharmapuri-636701, Tamil Nadu
Mob.: +91-94433 72349

Date: 13.07.2021

1758645

22 JUL 2021

P.S. to MOS(F-PC)

To,
Smt Nirmala Sitaraman Avl.,
Hon'ble Minister of Finance & Corporate Affairs
Govt. of India, North Block
New Delhi

Dear Madam,

Vanakkam

Sub: Request for Waiver of Import Duty & GST – reg.

I am writing the following for your kind attention and necessary action.

Baby K.S. Mithra (2 yrs) D/o K Satheesh Kumar is a patient of **Spinal Muscular Atrophy (SMA)** a genetic disorder since her birth. The child has difficulty in walking and delayed presentation in the lower motor neurons. Doctors have explained about the impact of this disease, which will increase day by day and will lead to shut down of the organs of the child and become life threatening. Council of Doctors also advised the drug **ZOLGENSMA** which has to be imported from abroad. The cost of the drug is Rs 16 crores and an import duty taxation of additional Rs 6 crore. Mr Satheesh Kumar is a middle class person, who cannot afford the medical expenses. Rs 13.5 crores has been raised through crowd funding, with a shortage of Rs 2.5 crores. GST cost of Rs 6 crore (which amounts to 35% of the cost of the medicine) is additional burden to the parents.

In this regard, I request you **waive the Import Duty and GST of the drug (ZOLGENSMA)**, which is essential for saving the life of the child.

Thanking you

Contact Person: Mr.k.Satheesh kumar.

Regards,

Contact Number:9500623402

Senthil Kumar

02/08/21

Ch. CBIC

MTR
JS (K2)



Dr. S. SENTHIL KUMAR, MDRU,
Member of Parliament (Lok Sabha)
Dharmapuri Constituency,
Tamil Nadu.

Old NoS (Finance)VIP/2021

Slary No. 1758645

Date 29/07/2021

Pr. Kumar (Customs Dept)

DS (GS)

Vair
2.8.21

DS (GS)

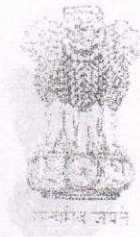
DS (GS)

ತೆಜಸ್ವಿ ಸೂರ್ಯ

तेजस्वी सूर्य

TEJASVI SURYA

MEMBER OF PARLIAMENT (LOK SABHA)
BENGALURU SOUTH - KARNATAKA



MEMBER:

Standing Committee on Information Technology
Joint Committee on Offices of Profit
Joint Parliamentary Committee on Personal Data
Protection Bill 2019

13

1782257
FM/VIPI/2021
10 AUG 2021

Li No DEL/TS/01017

13.07.2021
Bengaluru

To,
Smt. Nirmala Sitaraman
Hon'ble Minister for Finance & Corporate Affairs
Government of India, New Delhi - 110 001

Rev. Secy
Jenabul
9/8
PS to FM

Respected Ma'am,

SUB - Request to waive import duty & GST on Zolgensma Gene Therapy Drug from
Novartis for Baby Mithra K S

I am in receipt of a representation from Mr. Satheesh Kumar & Mrs. Priya Dharshini, parents
of Baby Mithra K S, who is 2 years old and is diagnosed with Spinal Muscular Atrophy (SMA)
Type 2. She needs this life saving drug which costs around INR 16 Crores and the GST and
import duty costs INR 6 Crores.

The family, through crowdfunding, has been able to collect INR 16 Crores for securing the
drug from Novartis. However, the family is unable to source funds for the GST & import duty
and have made multiple requests before the concerned authorities for waiver. Previously,
Government of India had waived import duty & GST on the same drug for Baby Teera Kamat
& Baby Ayaansh on humanitarian grounds.

In view of the above, I urge you to consider this request positively and waive the GST &
import duty on the said drug and instruct the authorities concerned to take necessary steps
on humanitarian grounds.

Immediate pls.

Yours sincerely,

R.S. Tejasvi Surya
(Tejasvi Surya)

Ch(Go)
Mansu
Encl.
not
received
Sampath

Comp. Cons
11/8/21
PS (ICD)
10/8/21
Shri Rajmeha

11/07/2021

Email

Harish Kumar

Fwd: Urgent - Tax waiver on Import duty and GST to purchase Zolgensma gene therapy drug from Novartis

From : Harish Kumar <uscus5-cbec@gov.in>

Thu, Jul 08, 2021 02:32 PM

Subject : Fwd: Urgent - Tax waiver on Import duty and GST to purchase Zolgensma gene therapy drug from Novartis

2 attachments

To : Rajanish Meena <rajanish.meena@gov.in>

From: satheeshk182@gmail.com

To: "Harish Kumar" <uscus5-cbec@gov.in>

Sent: Thursday, July 8, 2021 2:27:30 PM

Subject: Urgent - Tax waiver on Import duty and GST to purchase Zolgensma gene therapy drug from Novartis

Respected Sir/Madam,

We, Priya Dharshini and Satheesh Kumar, from Komarapalayam, Namakkal District, write to you as concerned parents of Mithra, our 2-years-old daughter diagnosed with Spinal Muscular Atrophy, Type 2. Hers is a severe, rare, early-onset genetic disorder that affects a child's nervous system and eventually kills the baby as the condition progresses.

We are working with our doctor Dr. Ann Agnes Mathew from Baptist Hospital, Hebbal, Bangalore, and the pharma company Novartis Gene Therapies to import Zolgensma, a lifesaving gene replacement therapy for Mithra. Our doctor has advised that based on her current weight, she is going to require 55 ml of the medicine, which needs to be imported from the United States of America. We confirm that this medicine is to be given to Mithra and will be imported for personal use. This is expected to come as 1 package with 10 vials of 5.5 ml doses of medicine each.

The medicine will need to be imported before the end of July and we have started the paperwork with the pharma company to initiate the procurement process.

We have raised the funds for the medicine through crowdfunding. We now request the government and the customs office that on humanitarian grounds please accept our request to provide customs duty and tax exemptions on this medicine import. The medicine, Zolgensma, is critical for Mithra's survival and this additional amount is not something we are able to afford.

Please do let us know the procedure to apply for tax exemption as Mithra has very little time.

Please see enclosed below:

1. Appeal to PMO highlighting our case and the dire condition of Mithra
2. Original doctor's prescription
3. Link on Import duty tax exemption for Spinal Muscular Atrophy drug

https://www.business-standard.com/article/current-affairs/drug-for-spinal-muscular-atrophy-already-exempt-from-import-duty-fm-121031900481_1.html

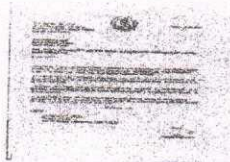
You can contact us at the below-mentioned numbers at anytime

15

1. Satheesh Kumar - +91 75986 06767 / +91 95006 23402 (Father)
2. Priya Dharshini - +91 95002 43444 / + 91 63790 76618 (Mother)
3. Vidhya - +91 87544 57670 (Aunt)

Thank you,

Priya Dharshini and Satheesh Kumar



Mithra_Appeal to PMO for tax waiver.jpeg
95 KB

Mithra_Prescription from the treating doctor.pdf
386 KB

From : satheeshk182@gmail.com

Thu, Jul 08, 2021 02:27 PM

Subject : Urgent - Tax waiver on Import duty and GST to purchase Zolgensma gene therapy drug from Novartis

2 attachments

To : Harish Kumar <uscus5-cbec@gov.in>

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We are working with our doctor Dr. Ann Agnes Mathew from Baptist Hospital, Hebbal, Bangalore, and the pharma company Novartis Gene Therapies to import Zolgensma, a lifesaving gene replacement therapy for Mithra. Our doctor has advised that based on her current weight, she is going to require 55 ml of the medicine, which needs to be imported from the United States of America. We confirm that this medicine is to be given to Mithra and will be imported for personal use. This is expected to come as 1 package with 10 vials of 5.5 ml doses of medicine each.

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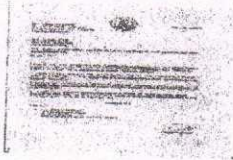
https://www.business-standard.com/article/current-affairs/drug-for-spinal-muscular-atrophy-already-exempt-from-import-duty-fm-121031900481_1.html

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1. Satheesh Kumar - +91 75986 06767 / +91 95006 23402 (Father)
2. Priya Dharshini - +91 95002 43444 / + 91 63790 76618 (Mother)
3. Vidhya - +91 87544 57670 (Aunt)

Thank you,

Priya Dharshini and Satheesh Kumar



Mithra_Appeal to PMO for tax waiver.jpeg
95 KB

 **Mithra_Prescription from the treating doctor.pdf**
386 KB