

Docket: 2016-2556(IT)I

BETWEEN:

SANDRA HUGHES,

Appellant,

and

HER MAJESTY THE QUEEN,

Respondent.

Appeal heard on March 14, 2017, at Calgary, Alberta.

Before: The Honourable Justice Patrick Boyle

Appearances:

Agent for the Appellant: John Adams

Counsel for the Respondent: E. Ian Wiebe

JUDGMENT

The appeal from the determination made under the *Income Tax Act*, notice of which is dated September 24, 2015, is allowed and the matter is referred back to the Minister of National Revenue for reconsideration and redetermination in accordance with the attached reasons for judgment.

Signed at Ottawa, Canada, this 27th day of February 2018.

“Patrick Boyle”

Boyle J.

Citation: 2018 TCC 42
Date: 20180227
Docket: 2016-2556(IT)I

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REASONS FOR JUDGMENT

Boyle J.

Introduction

[1] The Appellant, Sandra Hughes, has appealed the determination by the Canada Revenue Agency (“CRA”) that she was not entitled to claim a disability tax credit (“DTC”) in respect of her daughter Gwynneth.

[2] Ms. Hughes applied for the DTC in respect of her daughter in June 2015 using CRA’s form T2201, which included the required certification by Gwynneth’s doctor. In September 2015, CRA issued a notice of determination stating Gwynneth was not eligible for the DTC. The determination of non-eligibility was confirmed by CRA in June 2016 in response to the notice of objection filed by Ms. Hughes.

[3] The Appellant’s daughter was 15 years old when the doctor signed the DTC application. The application itself was not dated nor is there evidence of when it was filed or mailed. Had the determination been that her daughter was eligible for the DTC, the Appellant intended to begin claiming her as a DTC eligible dependent on her annual returns and to apply for a reassessment of her returns for the preceding 10 years as permitted by the *Income Tax Act* and the policy and practice of CRA.

[4] The Appellant’s daughter was born with phenylketonuria (“PKU”). PKU is a lifelong condition for which there remains no cure, only lifelong treatment. If left untreated, a child with PKU can be expected to suffer permanent severe brain damage.

[5] As described by Gwynneth’s medical geneticist and metabolic specialist in her letter of March 2017:

Phenylketonuria is an inherited *impairment* of the body’s ability to metabolize the amino acid phenylalanine. This is a genetic condition, meaning it is life long and starts at birth. This is a serious condition, as phenylalanine metabolism is a vital function. Without the ability to metabolize phenylalanine, the levels of phenylalanine in the body quickly rise (within a day) to toxic levels. Short term, high phenylalanine affects cognitive ability (executive function) and long term (in children) causes permanent severe brain damage.

People who do not have this impairment (i.e. do not have phenylketonuria) can metabolize phenylalanine, therefore they do not have to follow a phenylalanine restricted diet. People with phenylketonuria must follow the treatment plan and have blood phenylalanine levels monitored for their entire lives. If they consume a regular diet they will be causing brain damage to themselves.

[6] The treatment is not to remove all phenylalanine (“Phe”) from a PKU patient’s diet — even if that were a possibility. The human body requires a certain amount of Phe to develop and function normally. For healthy persons eating a normal diet, the metabolization of Phe allows the body to use about 10% of the Phe ingested and to eliminate the other approximate 90%. For those with PKU, their body must ingest each day only the specific lesser amount prescribed in order to develop and function normally, but absolutely nothing more as any excess will not be eliminated and will damage the brain.

[7] This treatment for PKU is well described in the recent decision of Justice Jorré in *Mullings v. The Queen*¹ as follows:

24 The therapy consists of managing the daily amount of Phe consumed very precisely while also ensuring a sufficient intake of all the other amino acids, apart from Phe, that constitute the necessary protein intake for the child. This is accomplished by a carefully managed combination of three components:

1. The prescribed formula (the medical formula) that Dr. Potter described as artificial nutrition — The formula provides a complete set of proteins

¹ 2017 TCC 133.

except for Phe and must be taken four times a day in the morning, at lunch time, in the afternoon and at bedtime. The formula consists of a prescribed amount of amino acid powder dissolved in a particular amount of water.

2. Special processed low protein foods (the medical foods) — For example, there are pasta products where the high protein component (such as flour) has been replaced with a low protein substitute (such as starch); unfortunately, the result is less palatable than normal pasta. These medical foods are quite expensive.
3. Limited quantities of ordinary foods that have little or no Phe as well as completely avoiding many foods that have high Phe.

[8] It is clear from CRA's initial determination of September 2015, and its May 2016 and June 2016 letters responding to the Appellant's objection, that Gwynneth was determined to be non-eligible because her impairment related to a dietary restriction and her treatment activities consisted of following a dietary regime.

The Law

[9] The relevant portions of the DTC legislation are:

118.3(1) Credit for mental or physical impairment — Where

(a) an individual has one or more severe and prolonged impairments in physical or mental functions,

(a.1) the effects of the impairment . . . are such that the individual's ability to perform a basic activity of daily living is markedly restricted or would be markedly restricted but for therapy that

(i) is essential to sustain a vital function of the individual,

118.3(1) Cr dit d'imp t pour d ficiency mentale ou physique —

Un montant est d ductible dans le calcul de l'imp t payable par un particulier en vertu de la pr sente partie pour une ann e d'imposition, si les conditions suivantes sont r unies :

a) le particulier a une ou plusieurs d ficiences graves et prolong es des fonctions physiques ou mentales;

a.1) les effets de la ou des d ficiences [...] sont tels que la capacit  du particulier d'accomplir une activit  courante de la vie quotidienne est limit e de fa on marqu e ou le serait en l'absence de soins th rapeutiques qui,   la fois :

(i) sont essentiels au maintien d'une fonction vitale du

particulier,

(ii) is required to be administered at least three times each week for a total duration averaging not less than 14 hours a week, and

(ii) doivent être administrés au moins trois fois par semaine pendant une durée totale moyenne d'au moins 14 heures par semaine,

(iii) cannot reasonably be expected to be of significant benefit to persons who are not so impaired,

(iii) selon ce à quoi il est raisonnable de s'attendre, n'ont pas d'effet bénéfique sur des personnes n'ayant pas une telle déficience;

...

[...]

there may be deducted in computing the individual's tax payable under this Part for the year the amount . . .

(1.1) **Time spent on therapy** — For the purpose of paragraph 118.3(1)(a.1), in determining whether therapy is required to be administered at least three times each week for a total duration averaging not less than an average of 14 hours a week, the time spent on administering therapy

(1.1) **Temps consacré aux soins thérapeutiques** — Pour l'application de l'alinéa 118.3(1)a.1), lorsqu'il s'agit d'établir si des soins thérapeutiques sont donnés au moins trois fois par semaine pendant une durée totale moyenne d'au moins 14 heures par semaine, le temps consacré à donner les soins est calculé selon les critères suivants :

(a) includes only time spent on activities that require the individual to take time away from normal everyday activities in order to receive the therapy;

a) n'est compté que le temps consacré aux activités qui obligent le particulier à interrompre ses activités courantes habituelles pour recevoir les soins;

(b) in the case of therapy that requires a regular dosage of medication that is required to be adjusted on a daily basis, includes (subject to paragraph (d)) time spent on activities that are directly related to the determination of the dosage of the medication;

b) s'il s'agit de soins dans le cadre desquels il est nécessaire de déterminer un dosage régulier de médicaments qui doit être ajusté quotidiennement, est compté, sous réserve de l'alinéa d), le temps consacré aux activités entourant directement la détermination de ce dosage;

(c) in the case of a child who is unable to perform the activities related to the administration of the therapy as a result of the child's age, includes the time, if any, spent by the child's primary caregivers performing or supervising those activities for the child; and

(d) does not include time spent on activities related to dietary or exercise restrictions or regimes (even if these restrictions or regimes are a factor in determining the daily dosage of medication), travel time, medical appointments, shopping for medication or recuperation after therapy.

...

118.4(1) Nature of impairment — For the purposes of subsection 6(16), sections 118.2 and 118.3 and this subsection,

(a) an impairment is prolonged where it has lasted, or can reasonably be expected to last, for a continuous period of at least 12 months;

(b) an individual's ability to perform a basic activity of daily living is markedly restricted only where all or substantially all of the time, even with therapy and the use of appropriate devices and medication, the individual is blind or is unable (or requires an inordinate amount of time) to perform a basic activity of daily

c) dans le cas d'un enfant qui n'est pas en mesure d'accomplir les activités liées aux soins en raison de son âge, est compté le temps que consacrent les principaux fournisseurs de soins de l'enfant à accomplir ces activités pour l'enfant ou à les surveiller;

d) n'est pas compté le temps consacré aux activités liées au respect d'un régime ou de restrictions alimentaires ou d'un programme d'exercices (même si ce régime, ces restrictions ou ce programme sont pris en compte dans la détermination du dosage quotidien de médicaments), aux déplacements, aux rendez-vous médicaux, à l'achat de médicaments ou à la récupération après les soins.

[...]

118.4(1) Déficience grave et prolongée — Pour l'application du paragraphe 6(16), des articles 118.2 et 118.3 et du présent paragraphe :

a) une déficience est prolongée si elle dure au moins 12 mois d'affilée ou s'il est raisonnable de s'attendre à ce qu'elle dure au moins 12 mois d'affilée;

b) la capacité d'un particulier d'accomplir une activité courante de la vie quotidienne est limitée de façon marquée seulement si, même avec des soins thérapeutiques et l'aide des appareils et des médicaments indiqués, il est toujours ou presque toujours aveugle ou incapable d'accomplir une activité courante de la vie quotidienne sans y consacrer un

living;

temps excessif;

...

[...]

(c) a basic activity of daily living
in relation to an individual means

c) sont des activités courantes de la
vie quotidienne pour un particulier :

(i) mental functions necessary
for everyday life,

(i) les fonctions mentales
nécessaires aux activités de la
vie courante,

(ii) feeding oneself or dressing
oneself,

(ii) le fait de s'alimenter ou de
s'habiller,

(iii) speaking so as to be
understood, in a quiet setting,
by another person familiar with
the individual,

(iii) le fait de parler de façon à
se faire comprendre, dans un
endroit calme, par une personne
de sa connaissance,

(iv) hearing so as to
understand, in a quiet setting,
another person familiar with
the individual,

(iv) le fait d'entendre de façon à
comprendre, dans un endroit
calme, une personne de sa
connaissance,

(v) eliminating (bowel or
bladder functions), or

(v) les fonctions d'évacuation
intestinale ou vésicale,

(vi) walking;

(vi) le fait de marcher;

(c.I) mental functions necessary
for everyday life include

c.I) sont compris parmi les
fonctions mentales nécessaires aux
activités de la vie courante :

(i) memory,

(i) la mémoire,

(ii) problem solving, goal-
setting and judgement (taken
together), and

(ii) la résolution de problèmes,
l'atteinte d'objectifs et le
jugement (considérés dans leur
ensemble),

(iii) adaptive functioning;

(iii) l'apprentissage fonctionnel
à l'indépendance;

...

[...]

(e) feeding oneself does not

e) le fait de s'alimenter ne

include

(i) any of the activities of identifying, finding, shopping for or otherwise procuring food, or

(ii) the activity of preparing food to the extent that the time associated with the activity would not have been necessary in the absence of a dietary restriction or regime; and

...

[Emphasis added.]

comprend pas :

(i) les activités qui consistent à identifier, à rechercher, à acheter ou à se procurer autrement des aliments,

(ii) l'activité qui consiste à préparer des aliments, dans la mesure où le temps associé à cette activité n'y aurait pas été consacré en l'absence d'une restriction ou d'un régime alimentaire;

[...]

[Je souligne.]

[10] In *Johnston v. Canada*,² the Federal Court of Appeal wrote:

10 The purpose of sections 118.3 and 118.4 is not to indemnify a person who suffers from a severe and prolonged mental or physical impairment, but to financially assist him or her in bearing the additional costs of living and working generated by the impairment. As Bowman T.C.J. wrote in *Radage v. R.* at p. 2528:

The legislative intent appears to be to provide a modest relief to persons who fall within a relatively restricted category of markedly physically or mentally impaired persons. The intent is neither to give the credit to everyone who suffers from a disability nor to erect a hurdle that is impossible for virtually every disabled person to surmount. It obviously recognizes that disabled persons need such tax relief and it is intended to be of benefit to such persons.

The learned Judge went on to add, at p. 2529, and I agree with him:

If the object of Parliament, which is to give to disabled persons a measure of relief that will to some degree alleviate the increased difficulties under which their impairment forces them to live, is to be achieved the provisions must be given a humane and compassionate construction.

² [1998] F.C.J. No. 169 (QL).

11 Indeed, although the scope of these provisions is limited in their application to severely impaired persons, they must not be interpreted so restrictively as to negate or compromise the legislative intent.

[Emphasis added.]

While *Radage v. Canada*³ is most often referred to in support of the DTC provisions being construed humanely and compassionately and “not narrowly and technically”, it should be noted that former Chief Justice Bowman in that same passage in *Radage* restated his view that the DTC provisions also “require a compassionate and commonsense application” (emphasis added).

[11] In the CRA form T2201 in evidence, CRA defines “life-sustaining therapy” as follows:

Life-sustaining therapy for your patient must meet **both** of the following conditions:

- Your patient needs this therapy to support a vital function, even if this therapy has alleviated the symptoms.
- Your patient needs this therapy at least 3 times per week, for an average of at least 14 hours per week.

Your patient must dedicate the time for the therapy — that is, the patient has to take time away from normal, everyday activities to receive it. If your patient receives therapy by a portable device, such as an insulin pump, or an implanted device, such as a pacemaker, the time the device takes to deliver the therapy **does not** count towards the 14-hour per week requirement. However, the time your patient spends setting up a portable device **does** count.

Do not include activities such as following a dietary restriction or regime, exercising, travelling to receive the therapy, attending medical appointments (other than appointments where the therapy is received), shopping for medication, or recuperating after therapy.

For 2005 and later years

- If your patient’s therapy requires a regular dosage of medication that needs to be adjusted daily, the activities directly related to determining and administering the dosage are considered part of the therapy (for example, monitoring blood glucose levels, preparing and administering the insulin, calibrating necessary equipment, or maintaining a log book of blood glucose levels).

³ [1996] T.C.J. No. 730 (QL).

- Activities that are considered to be part of following a dietary regime, such as carbohydrate calculation, as well as activities related to exercise, **do not count** toward the 14-hour requirement (even when these activities or regimes are a factor in determining the daily dosage of medication).
- If a child is unable to perform the activities related to the therapy because of his or her age, the time spent by the child’s primary caregivers performing and supervising these activities **can** be counted toward the 14-hour per week requirement. For example, in the case of a child with Type 1 diabetes, supervision includes having to wake the child at night to test his or her blood glucose level, checking the child to determine the need for additional blood glucose testing (during or after physical activity), or other supervisory activities that can reasonably be considered necessary to adjust the dosage of insulin (excluding carbohydrate calculation).

Examples of life-sustaining therapy:

- Chest physiotherapy to facilitate breathing
- Kidney dialysis to filter blood
- Insulin therapy to treat Type 1 diabetes in a child who cannot independently adjust the insulin dosage (for 2005 and later years)

The form T2201 also defines “markedly restricted” and “inordinate amount of time” as follows:

Markedly restricted — means that **all or substantially all of the time** (at least 90% of the time), and even with therapy (other than therapy to support a vital function) and the use of appropriate devices and medication, either:

- your patient is unable to perform one or more of the basic activities of daily living (see above); or
- it takes your patient an **inordinate amount of time** (defined in the introduction of this form) to perform one or more of the basic activities of daily living.

...

Inordinate amount of time — is a clinical judgement made by a qualified practitioner who observes a recognizable difference in the time required for an activity to be performed by a patient. Usually, this equals three times the normal time required to complete the activity.

[Emphasis added.]

Positions of the Parties

[12] The Appellant maintains that her daughter is eligible for the DTC on the basis that she received life-sustaining therapy daily which required on average 14 hours weekly of qualifying time, and but for which she would be markedly restricted in her mental functions necessary for everyday life.

[13] The Appellant also maintains that her daughter was markedly restricted in her ability to feed herself. Her daughter would be severely brain damaged if she fed herself or was fed food available in grocery stores or restaurants. She maintained that being fed the prescribed medical diet to deliver only the specific amount of Phe her body needed to develop and function normally, and for her brain not to be permanently damaged, required an inordinate amount of time.

[14] The Respondent's position is that "the Appellant's daughter's diet is not a therapy administered for a total duration averaging at least 14 hours a week".⁴ The Respondent maintained that the prescribed medical diet that delivered the specific amount of Phe along with other nutrients required for normal development and functioning did not constitute a therapy because it was specifically excluded as a dietary restriction or regime.

[15] The Respondent further maintained that the Appellant's daughter was not markedly restricted in her ability to feed herself since she had "no difficulty or impairment in physically feeding herself" and relied upon her doctor's certification that she had "no physical constraints to eating and drinking".⁵

[16] In addition to the notice of appeal and the reply, both parties provided detailed written submissions to the Court following the hearing, and provided further detailed written submissions to the Court in August 2017 following the decision of Justice Jorré in *Mullings*, above. In late September, the Respondent wrote to the Court with respect to its further and amended position regarding the *Mullings* decision for purposes of this appeal.

[17] The Appellant testified on her own behalf. In addition, the Court heard testimony from Nicole Pallone who described herself as a parent-expert on caring for PKU children. Ms. Pallone has spoken and presented posters on the topic of managing PKU in children at medical and scientific conferences including a PKU

⁴ Reply to the notice of appeal, paragraph 6g); Respondent's written submissions dated April 12, 2017, paragraph 2.

⁵ Respondent's written submissions dated April 12, 2017, paragraph 19.

Academy in Rome in 2012, the Genetic Metabolic Dietitians International Meeting in New Orleans in 2012, the National PKU Alliance in Philadelphia in 2012, the Garrod Symposium for Canadian Geneticists in Winnipeg in 2012, the American Society for Human Genetics in San Francisco in 2012, and the Society for Inherited Metabolic Diseases Symposium in California in 2014.

[18] Ms. Pallone wrote the “PKU Fact Sheet” as well as the “The ABC’s of PKU — What Early Childhood Educators and School Administrators Need to Know”, both published by Canadian PKU and Allied Disorders Inc. These publications provided helpful information to the Court. In addition, Ms. Pallone’s testimony corroborated the Appellant’s testimony regarding the needed activities in caring for a PKU child. The Respondent did not claim to be surprised by this evidence, did not object to any of it, and did not introduce evidence of its own. The Respondent was involved in the *Mullings* appeal several months earlier.

[19] The Respondent did not call any witnesses.

DTC Jurisprudence Involving PKU Children

[20] The Court was referred to two decisions of this Court involving DTC claims for persons afflicted with PKU.

[21] Both parties referred to the 2017 decision of Justice Jorré in *Mullings*. The *Mullings* case was decided in favour of the taxpayer. The only issue before the Court in that case was whether the therapy was administered for a total duration averaging not less than 14 hours a week of time spent on qualifying activities.⁶ There was no dispute in *Mullings* that the treatment the taxpayer’s child received for their PKU to deliver the precise amount of Phe was therapy. Similarly, it was not disputed that without that therapy the child’s ability with respect to a basic activity of daily living would be markedly restricted. It appears from the reasons that the marked restriction was considered to be with respect to the necessary mental functions and that the vital function for which the therapy was necessary to sustain was brain function.

[22] In deciding the sole issue of whether the 14-hour weekly therapy requirements were met, Justice Jorré concluded:

⁶ *Mullings*, paragraph 15.

1. The administration of the precise amount of Phe every day was therapy.
2. The administration of the treatment or therapy included:⁷
 - sourcing and storing medical formula and medical food;
 - planning and preparing X's meals and snacks including:
 - weighing food so as to measure, calculate, and log the amount of Phe from all sources prepared for X's consumption so as to ensure the correct amount of daily Phe consumption as well as
 - measuring and logging the formula to ensure adequate consumption of all the other amino acids (apart from Phe) constituting protein;
 - supervising X's consumption of food so the amount of Phe actually consumed is monitored;
 - if necessary, after a meal or snack, recalculating Phe consumption for the rest of the day and adjusting subsequent meals or snacks to take account of actual consumption (for example, if a food is not eaten or only partly eaten with the result that less food than planned was consumed, then it will be necessary to ensure more Phe is consumed by adding or substituting something; another example, where adjustments have to be made, is this: if, for instance, in spite of efforts to avoid this, X winds up eating some other child's food it may be necessary to try to make an offsetting reduction in Phe consumption for the day);
 - educating others, such as caregivers, teachers, classmates and other parents, regarding PKU so as to prevent consumption of more Phe than planned (for example, ice cream at a friend's home);
 - when picking up X from the care of others, finding out what medical formula and medical food and ordinary food was consumed — normally the Appellant will pick up any leftover meal or snack items so that they can be measured (weighed) and the amount of Phe consumed up to that point in the day can be recalculated for the purpose of making adjustments for the rest of the day;
 - attending various medical appointments with different doctors and the dietitian;

⁷ Mullings, paragraph 30.

- monitoring X's Phe blood level through weekly blood tests to ensure that the prescribed Phe-restricted diet is effective.

and included:⁸

1. Monitoring: blood Phe-level check (venous draw) at McMaster Children's Hospital (once/week)
2. Treatment: medical formula measurement and preparation
3. Treatment: consumption of medical formula/supervision of medical formula intake
4. Measurement and recording of medical formula actually administered/drunk
5. Measurement/weighing of Phe content to be consumed at each and every meal or snack at daycare only
6. Calculation of Phe in foods administered for meals or snacks at daycare only
7. Storage of food in daycare centre and pickup at end of day
8. Discussion with daycare staff (a.m. and p.m.) regarding consumption of food during the day, every day
9. Daycare staff logging food consumed daily
10. Measurement/weighing of food actually consumed at each meal or snack at daycare
11. Measurement/weighing of food not consumed at daycare
12. Discussion with daycare staff re: special snacks (e.g., birthdays, pizza day) or inadvertent consumption of Phe
13. Preparation of low Phe alternative for daycare special snacks (e.g., birthdays, pizza day)
14. Checking labels, determining and calculating Phe in new foods
15. Measurement/weighing of Phe content to be consumed at each and every meal or snack at home
16. Calculation of Phe in foods administered for meals or snacks at home

⁸ Mullings, Annex B.

17. Measurement/weighing of food actually consumed at each meal or snack at home
 18. Preparation/cooking for Phe-restricted diet (in addition to preparation of “normal” foods)
 19. Daily Phe consumption calculation prior to dinner to determine meal/portion permitted
 20. Daily Phe consumption post dinner to determine Phe to be added (or not) to final formula
 21. Supervision of Phe intake
 22. Maintain logbook of daily Phe intake
 23. Receipt of blood Phe level results via email
 24. Consultation with registered dietitian to adjust medical formula and/or allotted Phe intake
 25. Preparation for travel away from home (e.g., day trips, weekend visits, lengthy vacations)
 26. Researching and interviewing child care centres
 27. Time off of work for blood Phe checks (including travel)
 28. Clinic follow-up with metabolic physician, dietitian, genetic counsellor, and social worker (three-four visits/year)
 29. Ordering medical food and medical formula
 30. Unpacking, labelling and storing medical food (perishable and non-perishable) and medical formula
 31. Consult with physicians and/or pharmacists re: Phe in day-to-day medicines, antibiotics, and vaccines
 32. Consult with developmental pediatrician re: overall development and management of PKU (three visits/year)
3. The reference to medical appointments excluded from time spent on therapy by paragraph 118.3(1.1)(d) does not apply to a medical appointment where there is actual treatment or testing that is part of the treatment. That is consistent with CRA’s form T2201 which says

to exclude medical appointments other than appointments where the therapy is received.

4. Everything relating to the administration of the medical formula multiple times daily, including the related blood test, is part of the administration of the therapy (Nos. 1 to 4 and 23 above).
5. Attending to the Phe consumption in the medical food, including the time spent determining the amount of Phe to be consumed, and that actually consumed, as well as the time spent logging Phe intake is part of the administration of the necessary therapy and is not considered an excluded activity relating to dietary restrictions or regimes (Nos. 5, 6, 10, 11, 15, 16, 19, 20 and 22 above).
6. There may have been other activities that qualified as time spent on the administration of therapy that were not excluded, but it was not necessary to address them once the minimum 14-hour average had been established in the evidence in *Mullings*.

[23] The Respondent referred to this Court's 1996 decision in *Jasinski v. Canada*.⁹ The reasons in *Jasinski* have a description of PKU that is consistent with the evidence in the case before the Court and the reasons of Justice Jorré in *Mullings*, albeit much less detailed. The *Jasinski* case is of very limited relevance in this case for several reasons. First, it predated the amendments to the DTC provisions which extended them to impairments which would markedly restrict a daily living activity but for therapy. (This is addressed in footnote 9 of *Mullings*.) Second, the Court in *Jasinski* did not address whether the child was markedly restricted in feeding themselves, focusing instead on the fact that any impairment to mental functions remained a possibility and had not yet occurred. A third reason is that *Jasinski* predates the Federal Court of Appeal decision in *Johnston*, above, and the decision of former Chief Justice Bowman in *Radage*, above.

Issues to be Decided

[24] The issues to be decided are:

1. Do the activities relating to:

⁹ [1996] T.C.J. No. 647 (QL).

- (i) the administration of the required dosage of medical formula,
- (ii) the ingestion of the required Phe in the consumption of the medical foods, and
- (iii) the ingestion of Phe via the consumption of ordinary foods with very low naturally occurring Phe

constitute therapy?

- 2. (i) But for this therapy, would Gwynneth be markedly restricted in her mental functions necessary for everyday living (paragraph 118.3(1)(a.1))?
- (ii) Is the therapy essential to sustain one of her vital functions (subparagraph 118.3(1)(a.1)(i))?
- 3. Is any of the time spent on activities described in 1(i) through (iii) above excluded as medical appointments or as activities relating to dietary restrictions or regimes?¹⁰
- 4. Did the taxpayer and her daughter spend on average at least 14 hours weekly on administering the prescribed PKU treatment?
- 5. In the alternative, if the taxpayer is not successful in any of 1 to 4 above, is the effect of Gwynneth's PKU that she is markedly restricted in feeding herself? More particularly, is the phrase "feeding oneself" limited to the ability to prepare food and to use cutlery or hands to take food from plate to mouth and to chew and swallow it — even in a case where most food found in an ordinary home's cupboards or in grocery stores or in restaurants will have severe adverse consequences to mental functioning and development?

The Facts/Evidence

¹⁰ Following the *Mullings* decision, the Respondent wrote to the Court that "for the purposes of this appeal" (my emphasis) the Respondent did not take issue with the *Mullings* interpretation of the phrase "activities related to dietary restrictions or regimes". It seems unwise after hearing the evidence and argument and receiving written submissions and follow-up written submissions to not proceed to decide this issue in this case.

[25] Gwynneth's PKU disorder and her liver's inability to properly metabolize Phe were detected at birth and her treatment began immediately. The Appellant was told at that time, left untreated, her daughter would most likely not develop beyond the mental faculties of a three-year old.

[26] Gwynneth was assigned to a medical team at the Metabolic Disorders Clinic of Alberta Children's Hospital comprised of a medical doctor having her specialty in genetics, two registered dietitians and a nurse, along with a social worker for counselling as required.

[27] PKU is a rare genetic disorder affecting about one in 15,000 Canadians. It is diagnosed through the newborn screening heel prick program administered routinely at birth.

[28] Phe is one of the many amino acids found in most dietary proteins. It is essential to human development and proper brain function. For those with a PKU disorder, Phe is not able to be properly processed by the liver resulting in toxic accumulation in the blood and brain.

[29] Medical treatment for PKU is prescribed by the geneticist who determines the specific daily Phe intake requirement, the exact amount of medical formula or formulas to be consumed three to four times daily, as well as the daily caloric intake. These are revised and replaced regularly as a result of regular blood testing being done to identify the Phe levels in the blood. Blood is generally taken twice weekly in babies leading to weekly and, by 2015 in Gwynneth's case, every two weeks. The minimum is monthly which is where Gwynneth is at now that she is on the pharmaceutical Kuvan. This blood work is done at the hospital not at home, as there are no home blood testing kits or methods available yet. Blood testing has to be done more often at times as Phe levels are affected by teething, growth spurts, sports activities, illness, other medications, puberty, pregnancy, etc.

[30] The daily caloric intake has to be identified as, if the body is not ingesting enough calories, it begins to burn existing body mass which includes proteins high in Phe causing a child's Phe level to spike. The missing calories are made up in the medical formula, the medical foods as well as some low protein ordinary food.

[31] Administration of the necessary Phe requires weighing absolutely everything that goes into the child's mouth and calculating the Phe of everything that goes into the child's mouth. Since children are not 100% cooperative in eating what they are served, this extends to weighing leftovers and recalculating.

[32] Gwynneth's prescribed daily Phe amount in 2015 was in the 300 mg range. The Phe must be calculated and monitored to the nearest milligram, meaning there is only a fraction of 1% tolerance in achieving the prescribed amount and not anything less or anything more.

[33] The calculation of the Phe involves taking the weight of each particular food item serving, finding its protein content as a function of weight for the particular item from extensive charts that are available, and then applying a factor that reflects the amount of Phe in food protein. Some food products and medications contain disproportionately high Phe, such as anything that has aspartame as an ingredient, and separate charts must be consulted for these.¹¹ All new medications require a consultation with one of the Metabolic Disorders Clinic's registered dietitians.

[34] This also requires teaching others how to protect Gwynneth's brain — all who will be giving any food to her such as daycare providers, school teachers, grandparents, friends, Gwynneth's friends' parents, and other family members.

[35] The restricted PKU medical diet is comprised of three distinct components:

- (i) the medical formula,
- (ii) the specially produced medical food,
- (iii) no or low protein ordinary food items.

The Medical Formula

- The restricted PKU diet is very low in proteins which results in a lack of certain other minerals and nutrients. This creates the need to supplement the diet with specialized Phe-free amino acid formulas, as well as the specially produced low protein medical foods below. In Gwynneth's case, her prescription was for a mix of two dry formulas to be mixed with water and administered three or four times throughout each day. (For some children, it is prescribed to be mixed with a small amount of cow's milk, in which case it will also be a source of Phe.)

¹¹ Aspartame does not have significant protein content, but it is comprised of about 50% Phe.

- These are dispensed only with a prescription. The cost of these medical formulas is covered by all provinces' health plans.

The Medical Food

- Medical food consists of specially produced food items in which there is either very little protein, or from which most of the proteins have been removed (protein-depleted). It is distributed completely outside the normal food distribution chain through a few Canadian distributors. It is fully funded in all Canadian provinces once approved by prescription from a metabolic disorders clinic. In Gwynneth's case, her doctor states they are supplied by the Alberta Health Services' Inherited Metabolic Diseases Program. For both Ms. Pallone in British Columbia, and the Appellant in Alberta, the hospital unit informed the National Food Distribution Centre's Metabolic Nutrition Program in Quebec that their children qualified to order the food directly and the province made payment directly to the distributor. In the *Mullings* case, the distribution centre for Ontario was Toronto's Sick Children's Hospital.
- The medical food is regulated in Canada and comes with prominent warnings that it is to be used only under medical supervision. These warnings included phrases such as:
 - “For use solely under medical supervision in the dietary management of conditions which require control or restriction of protein intake.”,
 - “[This product] has been specially developed as a medical food for the dietary management of conditions requiring restriction or control of protein. Use only under medical supervision.”, and
 - “IMPORTANT WARNING: The product must be consumed as part of an integrated dietary plan approved by a physician and must not be used as unique source of nutrition.”.
- These medical foods are used only in preparing food for the PKU patient. They include items described as pastas, rice, wafers, burger mix, hot dog mix, imitation scrambled egg, imitation macaroni and cheese, crackers, baking mix, cereals, and various bread products as well as “Dari-Free” milk. They often require significantly more cooking time than regular foods.

- The medical foods are used to deliver Phe in small amounts as required for the PKU patient, combined with other necessary nutritional ingredients.
- It is clear from the approval email from one of Gwynneth's registered dietitians at the hospital that the approval "prescriptions" are only for certain of the available foods and in quantities dictated by Gwynneth's condition and changes to it.

No or Low Protein Ordinary Foods

- There are some foods which are naturally very low in proteins. These are used to deliver Phe to the PKU patient while being able to provide a better balanced nutritional diet overall. Even with these "ordinary foods", the Phe level has to be identified and logged, etc. as part of Gwynneth's daily Phe intake in ensuring she receives precisely the prescribed Phe amount. These ordinary foods are able to be prepared for other family members' meals at the same time and enjoyed by other family members. However, all ingredients require careful and precise measure, and Gwynneth's servings need to be isolated, weighed, measured, converted and logged, etc.

[36] The Appellant described life since Gwynneth was diagnosed as a baby as weigh, measure, convert, eat, repeat, each bite, every single thing, all day, each day.

[37] The last meal of each day, bedtime snack, is when the balance of the necessary daily Phe is administered. It is administered as food, not liquid.

[38] All of the administration of the dietary treatment was performed by the Appellant until Gwynneth was 10. At age 10, the Appellant began involving Gwynneth with managing her PKU diet treatment on a supervised basis. It was only after Gwynneth turned 15, i.e. after the years in question, that Gwynneth was able to manage her PKU without supervision. This means that between the ages of 10 and 15, both the PKU child and the parent were involved in the administration of the treatment.

[39] Since 2015, Gwynneth has been on Kuvan which is a pharmaceutical that contains the missing enzyme BH₄ that is normally responsible for metabolizing Phe into tyrosine in the body. This has somewhat reduced the time needed to

administer the prescribed treatment as it has allowed Gwynneth to eat slightly more ordinary low-Phe foods since she can tolerate somewhat more Phe. The mix of medical food to ordinary food over the years has ranged from 90 medical:10 ordinary when she was younger, to 60:40 at age 15, to 40:60 now that she is now on Kuvan.

Average Weekly Time Estimates

[40] The Appellant prepared a one-page chart estimating the time spent on the treatment and management of Gwynneth's PKU. It is a one-page point form description of 19 activities together with an estimate of the total weekly time in minutes spent on each on average.

[41] The Appellant described this in her evidence, was cross-examined on it and answered my questions seeking clarification on it. It remains at best an estimate. It therefore has a number of limitations which were identified in Court.

[42] The one limitation stated on the form itself is that these estimates do not include the additional time and activity required when Gwynneth has any form of sickness. The time spent to manage her therapy increases when she is ill as more frequent blood work and heightened vigilance overall are required. This includes significant illnesses as well as sickness that are able to be readily treated with over-the-counter medications.

[43] Most significantly perhaps, this was prepared in the months leading up to the trial to reflect the state of affairs when Gwynneth was about 14 to 15 around the time the application was made. It was evident in the testimony that a number of these activities required significantly more time in prior years when Gwynneth was younger. I do not believe a proper determination should be made by limiting the review to the particular year the request for a determination is made — when Gwynneth turned 15 — given that the determination will apply to the 10 prior years also — when Gwynneth was as young as 5.

[44] In addition, the evidence was clear that between the ages of 10 and 15 both Gwynneth and the taxpayer were involved in the administration of her PKU treatment as it was necessary for the taxpayer to begin ensuring her child would be able to manage her PKU treatment on her own as she grew into adulthood. This would understandably be a lengthy process. Since both were involved, her estimate would need to be significantly higher at the start of this process, reducing gradually over this five-year period. This is not reflected in the estimates.

[45] There are a number of activities identified in the list Justice Jorré accepted in *Mullings*, which consistent with the evidence in this case must have been undertaken and form a part of Gwynneth's treatment, but do not appear to be reflected in the one-page chart.

[46] As described in greater detail below, in two instances on this chart, arithmetic errors were made in converting annual estimates to hours per week.

[47] As described below, not all time spent on activities related to the administration of the treatment will qualify, given the exclusions in the DTC legislation.

[48] The line for blood work indicates the amount is 15 minutes weekly on the basis that the blood work was once a month. It is clear from the evidence that blood work only commenced being completed once a month after Gwynneth started on Kuvan which was after the application was made. Before that time, it was twice monthly as described above, and had earlier been weekly. I find that a proper time estimate to have been entered on this chart should have reflected at least twice monthly and therefore at least 30 minutes per week.

[49] The Respondent's concerns with the activities and the time estimates in the chart are set out in paragraphs 18 to 22 of the Respondent's Further Written Submissions of August 17, 2017 (and reconfirmed in the Respondent's letter to the Court of September 25, 2017). These read as follows:

The Appellant does not meet the 14-hour minimum in any event

18. Even if this court applies Justice Jorré's reasoning in *Mullings*, the Appellant has not demonstrated that she meets the 14-hour minimum threshold.
19. The Time Chart states the Appellant spends an average of 15.79 hours per week managing her daughter's PKU. In cross-examination, the Appellant conceded that the Time Chart overestimated time related to several activities.
20. The Appellant allocated 90 minutes per week to time allocated to "preparation for travel away from home (e.g. weekend trips, student work exchange in Montreal, lengthy vacations)" and 60 minutes per week to "educating caregivers (e.g. host family and YWCA during work exchange in Montreal)". On cross-examination, she conceded that these activities would take place only a few times a year, rather than on a weekly basis.

These activities must be removed from the Appellant's estimated average time per week spent on therapy.

21. The Time Chart also included 30 minutes per week for "travel time to go to courier depot to pick up medical foods and medication". Paragraph 118.3(1.1)(d) excludes travel time from being counted toward the 14-hour minimum. This activity cannot be considered in determining the weekly average time.
22. When these activities are removed, the average time per week spent on therapy for the Appellant's daughter is 12.78 hours (767 minutes). As such, the Appellant does not meet the 14-hour weekly minimum average required for entitlement to the DTC.

[50] The Respondent is correct that the 30 minutes of travel time weekly to pick medical foods and medication from the courier depot cannot be counted by virtue of paragraph 118.3(1.1)(d).

[51] The Respondent is correct in identifying that the 90 minutes and 60 minutes weekly time allocated to educating caregivers and preparation for travel away from home were miscalculated, clearly inadvertently, by the Appellant in pulling together the one-page chart. However, the evidence is very clear that the Court worked through this with her and the correct numbers should not be zero as suggested by the Respondent, but should be reduced to 10 minutes and 6 minutes based upon her clear and direct answers to the questions once the problem was identified.

[52] The corrected chart to reflect no travel time to pick up medical foods and medication, and the proper numbers for preparation for travel and educating caregivers, as well as blood work, would be 798.5 minutes or 13.3 hours.

[53] I find that the evidence would reasonably support an increase in the 5% to 10% range to reflect the limitations I have described above other than the miscalculations now corrected for. That clearly places the qualifying time spent on administration of Gwynneth's PKU therapy during the relevant period exceeding 14 hours weekly on average.

[54] In the context of the DTC limitation describing "a total duration averaging not less than 14 hours a week" for all of the activities relating to the administration of medically prescribed therapy, however complicated or complex that may be in a particular situation, is contextually very different statutory language of measurement than, say, the "distance between the old residence and the new work

location is not less than 40 kilometres greater than the distance between the new residence and the new work location”. The latter moving expense language describes a finite readily measurable particular distance. In contrast, in the context of lifelong, ongoing treatment which varies with illnesses, growth spurts, other medications, etc. that is required to be satisfied annually at tax time using a weekly average for activities that must occupy at least one-twelfth of the year to qualify (the equivalent of a month’s worth of activity, or approximately two months of the year’s daylight hours), the concept of significant digits needs to be approached differently to reflect that differing context. If something must be at least 40 kilometres between point A and point B, clearly 39.75 will not suffice. In contrast, where the average of what is described in the DTC legislation with respect to life-sustaining therapy, where it would be entirely unreasonable to expect persons to keep time logs of their actual activities on a daily basis for accurate and precise measurement, I would be inclined to think that the concept of significant digits for measuring total average hours is solely whole numbers. On that basis, even without a 5% to 10% increase I have found warranted in this case, I would be inclined to think that anything 13.5 hours or greater estimated with the inherent limitations that the statute clearly contemplates, should satisfy the 14-hour requirement.

[55] Another example where greater precision could be expected is with respect to travel and meal expenses for employees where the limitation is expressed as the taxpayer be “required by the taxpayer’s duties to be away, for a period of not less twelve hours, from the municipality”. Here again, the measured item, being a period of not less than 12 hours, is clearly to be calculated with respect to each meal claimed and is therefore to be looked at on a daily basis in which case there would be a single period of time to be measured. This would also require a greater degree of accuracy and rigidity in deciding if the requirement was met given that the time the individual was away from his or her municipality on a particular day is either greater than 12 hours or it is not. Obviously, in administering the *Income Tax Act*, CRA is free to recognize that daily calculations for each work day over the course of a year covered in a particular return may not in practice require such exactitude.

[56] The Court in this case, however, is focusing on the language used in the statute and is interpreting textually, contextually and purposively the 14-hour average weekly requirement for someone who has an impairment that is required to be prolonged, which is defined as lasting for a continuous period of at least 12 months, and which gives rise to an ongoing and continuous marked restriction

in performing basic activities of daily living or mental functions necessary for everyday life.

Answers and Conclusions

1. Therapy/Soins thérapeutiques

[57] I conclude that the proper meaning of the word “therapy” (soins thérapeutiques) in the DTC provisions, read within the context of that provision in the DTC provisions, and in a manner consistent with the purpose of the DTC provisions which has already been determined by the courts, simply means the care or treatment of a physical or mental condition. That is consistent with dictionary definitions of the term, its use in common parlance including when talking about medical matters, and best achieves the purpose of the amendments to the DTC provisions which introduced the “but for therapy” extension to the scope of persons eligible to claim it. It is also consistent with the decision of Justice Jorré in *Mullings*. The Respondent did not put forward any substantive argument that this was not an appropriate definition or application.

[58] I agree with Justice Jorré’s more detailed conclusions regarding the scope of qualifying activities in the case of the administration of therapy for a PKU child in *Mullings*. (I also agree with his conclusions on what does not qualify discussed below under heading 3.)

[59] This is also consistent with CRA’s published pronouncements and illustrative examples of the scope of the term “therapy” (soins thérapeutiques).

2. Marked Restriction in Mental Functions/Essential to Sustain a Vital Function

[60] It is clear on the evidence that absent this therapy Gwynneth would have potentially devastating and irreversible adverse consequences to her proper mental development and functioning. Clearly the brain and its mental functions are vital and its normal functioning is sustained by this therapy.

3. Excluding Dietary Restrictions or Regimes and Travel Time

[61] None of Gwynneth’s treatment related to what can fairly be described as simply a dietary restriction, much less a dietary regime or anywhere close to carbohydrate reduction or calculation. I agree with the reasons of Justice Jorré in *Mullings* that, in the case of administering the necessary treatment of a PKU child

with a PKU impairment as extensive as Gwynneth's and the Mullings child, the overall counting and managing of Phe consumption through both medical foods and ordinary foods is much more like administering a medication than it is like managing a diet. I agree that this should extend to the time spent determining the amount of Phe to be consumed, determining the amount of Phe actually consumed, and logging the Phe intake.

[62] Travel time is clearly an excluded activity even though a necessary part of the therapy. Travel time has been removed in computing the average weekly time spent on qualifying activities above for Gwynneth's PKU treatment.

4. The 14-hour Average Weekly Requirement

[63] For the reasons described above, I have found on the evidence in this case that the 14-hour average requirement was met for the years up to the year the DTC eligibility application was made (2015).

[64] This conclusion does not necessarily remain unchanged in the future. This may depend on the continuing success of Kuvan or other pharmaceuticals in treating Gwynneth's disorder. It may depend upon changes in her overall health or the scope of her PKU disorder. It may also be that as a capable and experienced adult she is able to more efficiently administer the treatment herself.

[65] The 14-hour requirement is particular to each taxpayer and will not necessarily be met by each person afflicted with PKU even as a child. The evidence was clear that PKU disorder is not an all-or-nothing inability to process Phe but that different people have different levels of inability to process Phe. This requirement will continue to have to be met on a case-by-case basis.

5. Marked Restriction in Feeding Herself

[66] I do not need to decide this last question in this case. However, in circumstances such as Gwynneth's PKU disorder, I would be very much inclined to think that feeding Gwynneth in her particular circumstances required an inordinate amount of time.

[67] The DTC provision contemplates a person whose impairment may markedly restrict their ability to feed themselves by requiring an inordinate amount of time to do so. There is no clear or apparent reason to think that this should be limited to impairment of the arms, jaw, or mouth, or related motor skills. An impairment that

limits what the person is capable of processing as nutrition to fuel the body without causing severe and permanent bodily damage might well also be considered in giving a humane, compassionate and commonsense interpretation and application of this DTC provision.

[68] The appeal is allowed.

Signed at Ottawa, Canada, this 27th day of February 2018.

“Patrick Boyle”

Boyle J.

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