AN UPDATE ON THE SOCIAL SECURITY ADMINISTRATION’S COMPASSIONATE ALLOWANCE PROGRAM

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Background of Compassionate Allowance Program

The Social Security Administration (Social Security) initiated the Compassionate Allowance program (CAL) in October 2008 as a means of expediting the processing of Social Security disability claims for applicants whose disabilities are so severe that their conditions obviously meet Social Security’s strict standards. CAL was designed to quickly identify diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal, but sufficient, objective medical information. Social Security’s goal was to ensure that individuals who are clearly disabled receive a decision within twenty days of filing an initial application.

Creation of the CAL program followed the implementation of an earlier initiative, the Quick Disability Determination (QDD) program, which was piloted in 2006 in the New England states and rolled out nationally in September 2007. The QDD pilot established the efficiency of computer automated screening tools, allowing state Disability Determination Services (DDS) to process flagged cases in a twenty day processing period. With QDD, eligible cases are selected via a computer “Predictive Model” (PM) that analyzes claim specific components, including the probability that the claimant is disabled, whether evidence of the claimant’s allegations is expected to be easily and quickly verified, and whether the case can be processed quickly by DDS. During the pilot, QDD cases consisted of slightly less than 3% of all new cases. Of those cases, 97% were decided in twenty-one days and the average decision was made in eleven days. However, Social Security noted that in the QDD pilot, the majority of cases were cancer diagnoses because the PM did not yet cull a wide enough variety of diseases.

In its continuing effort to reduce the Initial Claim backlog, Social Security implemented QDD nationally in 2007 and then began work on the CAL program. Like QDD, CAL uses a computer PM. However, CAL is based solely on diagnoses, whereas QDD relies on a multi-factorial model to determine if there is a strong likelihood that a disability finding is proper. QDD cases must have a high enough score from the PM to be considered a QDD. On the other hand, a CAL case is identified when a claimant alleges a CAL impairment in the Initial Claim application.

In October 2008, Social Security introduced CAL with a list of fifty medical impairments that would automatically qualify a case for expedited processing. The initial list of

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1 POMS DI 23022.015.
2 POMS DI 23022.010.
5 POMS DI 23022.017.
Compassionate Allowance conditions was developed as a result of information received at public outreach hearings, public comment on an Advance Notice of Proposed Rulemaking, comments received from the Social Security and DDS communities, and the counsel of medical and scientific experts.\(^6\) The hearings included presentations on Rare Diseases on December 4-5, 2007 and Cancers on April 7, 2008. The original fifty conditions included twenty-five cancer diagnoses and twenty-five other rare diseases and syndromes. Many of the conditions were juvenile diseases and pertained only to SSI applications for children’s benefits. Social Security listed the CAL conditions in the Program Operations Manual System (POMS), rather than the Federal Register. Each condition has a POMS citation, which includes a description of the condition, alternate names, diagnostic testing and coding, treatment and progression of the disease, as well as suggested medical evidence of record for evaluation of the claim.\(^7\)

The combined number of QDD and CAL allowances in 2008 was 3.8%. Social Security set targets for combined QDD and CAL allowances for 2010 at 4.5% and for 2011 at 6.5%, with an ultimate goal to fast track 6% to 9% of all IC applications by 2012. That would have benefited a quarter of a million applicants each year.\(^8\)

**New CAL Impairments Since 2008**

Over the last five years, Social Security has expanded CAL by increasing the list of CAL impairments from fifty to two hundred. On March 1, 2010, Social Security added thirty-eight conditions to the list of Compassionate Allowances after holding additional outreach hearings on Brain Injuries and Stroke on November 18, 2008, Early Onset Alzheimer’s Disease and Related Dementias on July 29, 2009, and Schizophrenia on November 18, 2009. The additional impairments added to CAL in 2010 ranged from adult brain disorders, including early-onset Alzheimer’s disease, to more rare diseases. When announcing the additional CAL conditions, then Commissioner of Social Security Michael Astrue stated: “The expansion we are announcing today means tens of thousands of Americans with devastating disabilities will now get approved for benefits in a matter of days rather than months and years.” Commissioner Astrue indicated that Social Security will continue to hold hearings to determine what other diseases and conditions can be added to the list of Compassionate Allowances.\(^9\)

Social Security did hold additional outreach hearings, including one on Cardiovascular Disease and Multiple Organ Transplants on November 9, 2010 and Autoimmune diseases on March 16, 2011. At the hearing for autoimmune diseases, SSA welcomed testimony from non-profit organizations, disabled individuals, doctors and research scientists. The American Autoimmune Related Diseases Association, Inc. presented information and requested that Social Security consider multiple autoimmune conditions for the CAL program, including central nervous system lupus, severe lupus nephritis, progressive multiple sclerosis, catastrophic antiphospholipid syndrome, systemic

\(^6\) [http://www.socialsecurity.gov/compassionateallowances](http://www.socialsecurity.gov/compassionateallowances).
\(^7\) POMS DI 23022.080-23022.535.
\(^9\) See [http://www.socialsecurity.gov/compassionateallowances/newconditions.html](http://www.socialsecurity.gov/compassionateallowances/newconditions.html).
scleroderma, autoimmune aplastic anemia and severe, non-responsive Crohn’s disease. The Lupus Foundation of America also presented information and urged Social Security to add lupus to the list of Compassionate Allowances. A scleroderma association and the Arthritis Foundation made similar pleas for Social Security to add scleroderma and rheumatoid arthritis to the CAL list. Doctors provided testimony regarding current science, research and clinical treatment of autoimmune diseases; patients testified to the difficulties they experience living with various autoimmune diseases.

On October 13, 2011, Social Security added thirteen new conditions involving the immune system and neurological disorders to the Compassionate Allowance list. Commissioner Astrue announced the new conditions at the U.S. Conference on Rare Diseases and Orphan Products, stating that the Compassionate Allowance Program had assisted with the quick approval of 60,000 people in the past fiscal year. The 2011 additions included Malignant Multiple Sclerosis, Lewy Body Dementia, Multiple System Atrophy and ALS/Parkinsonism Dementia Complex.10

On April 11, 2012, Social Security announced fifty-two new Compassionate Allowance conditions, primarily involving neurological disorders, cancers and rare diseases. Announcing the new conditions at the World Orphan Drug Congress, Commissioner Astrue stated that SSA processed nearly 173,000 CAL applications since the program began in October 2008.11 The new impairments included Carcinoma of Unknown Primary Site and Malignant Melanoma with metastases.

Social Security added thirty-five conditions to the CAL list on December 6, 2012, bringing the total number of impairments to two hundred. The additional impairments included Huntington’s disease, a progressive and always fatal disease that affects nearly 30,000 people in the U.S.12 Commissioner Astrue stated “Nearly 200,000 people with severe disabilities nationwide have been quickly approved, usually in less than two weeks, through the program since it began in October 2008.”13

Unfortunately, Social Security has no plans to hold new outreach hearings in the near future due to budget restraints. However, Social Security’s CAL team continues working with internal and external medical experts, the National Institutes of Health and other health organizations and advocacy groups to identify and research potential CAL conditions.14

Processing of CAL Cases

Cases are selected for CAL processing based on the claimant’s allegations listed on the Disability report, Form SSA-3368 or Form SSA-3820. Most CAL cases are identified by

10 http://www.socialsecurity.gov/pressoffice/pr/ss-expands-compassionate-allowances.html, 10/13/11.
12 http://www.socialsecurity.gov/pressoffice/pr/ss-expands-compassionate-allowances.html, 7/13/12.
13 http://www.socialsecurity.gov/pressoffice/pr/ss-expands-compassionate-allowances.html, 12/6/12.
the PM upon Electronic Disability Collect System transfer to the DDS at the initial claim adjudicative level. Similar to the QDD process, CAL cases will receive expedited processing. In fact, the POMS instruct examiners to follow QDD processing guidelines in CAL cases. Cases selected for CAL processing can simultaneously be classified and processed as a QDD, Presumptive Disability and/or Terminal Illness (TERI) case. If one of these other classifications is ruled out during the evaluation process, the CAL case is still entitled to expedited processing.

Social Security made changes to help decrease the processing times for CAL claimants. In July 2011, Social Security reduced the paperwork burden for applicants with CAL conditions by eliminating the work and education history questions from the application, recognizing that this information is often not needed to make a decision on disability claims for individuals with CAL conditions due to their severity of conditions. In addition, in April 2012, SSA provided an option for all claimants who file for benefits online to electronically sign and submit their Authorization to Disclose Information to the Social Security Administration (Form SSA-827), which allows for speedier medical development.

**CAL’s Impact on Disability Claimants**

As stated above, when Social Security initiated CAL in 2008, the ultimate goal was the fast tracking of 6% to 9% of Initial Claim applications by 2012. This goal was subsequently adjusted to a target of 5.5% of Initial Claim applications. Per Social Security’s 2012 Performance and Accountability Report, in fiscal year 2012, Social Security processed 3,206,869 Initial Claims. Social Security identified 5.8% of these claims as CAL or QDD cases. Thus, SSA slightly exceeded its adjusted goal that 5.5% of Initial Claim applications receive fast tracking in 2012. However, given the total number of Initial Claim applications filed in 2012, CAL and QDD only benefited about 185,998 disabled individuals. The benefit to those claimants was indeed significant. The processing time for their applications averaged less than two weeks, as opposed to one hundred and two days for all other claimants. However, given the initial expectations that CAL would benefit a quarter of a million applicants each year, the program has yet to make a significant improvement for the majority of disabled individuals.

Although the additions to the CAL list in 2011 and 2012 provide opportunities for more disabled adults to have their claims expedited, the overall list of impairments is still limited. Approximately half of the two hundred listed CAL impairments are childhood diseases or congenital conditions that do not directly apply to adult disability claims. Furthermore, while some of the CAL impairments are adult diseases, they are extremely

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15 POMS DI 11005.604.
16 POMS DI 11005.604.
18 Id.
19 Id.
rare. For example, Fibrodysplasia Ossificans Progressiva is a disorder in which muscle and connective tissue are gradually replaced by bone. It is believed to occur in approximately one to two million people worldwide.\textsuperscript{22} Another CAL impairment, Fatal Familia Insomnia, has been documented in a just handful of families.\textsuperscript{23} Perry Syndrome, a progressive brain disease, has only affected 50 individuals worldwide.\textsuperscript{24} Thus, although Social Security has added many impairments to the CAL list, some of these conditions are so rare that in reality, few of the millions of claimants filing initial claim applications each year will be able to take advantage of the program.

As representatives of disabled adults, it is our experience that CAL has the most impact on our clients who suffer from cancer and neurological impairments. For example, in the past few years we have seen almost a 50\% reduction in the processing time of CAL impairments such as Early-Onset Alzheimer’s Disease and Ovarian Cancer. The improvement in the processing time of these conditions is significant as cancer is increasingly becoming an alleged disabling impairment. The 2013 Council for Disability Awareness Long Term Disability Claims Review reported that cancer increased as a cause of new disability claims in 2012, and is the second leading cause of new disability claims.\textsuperscript{25} The National Cancer Institute predicts that 1,660,290 men and women will be diagnosed with cancer and 580,350 men and women will die of cancer in the United States in 2013.\textsuperscript{26} Thus, as the CAL impairment lists contains multiple types of cancer, with over twenty cancers added in 2012, the program should have a broad impact on this specific population.

The increase in claim processing speed ensures that some severely disabled individuals receive their monetary Social Security disability benefits within weeks of filing their claims. This acceleration provides a cost savings for LTD carriers, both in terms of money paid out and resources devoted to servicing claims that are generally not in dispute. Furthermore, many disability claimants suffer severe financial hardship and need other support services besides Social Security disability benefits. People suffering from a CAL impairment often require greater than normal expenses, such as adult daycare for those with mixed dementias or Early Onset Alzheimer’s. On the state and municipal levels, several relief programs for medical care and other services are contingent on a determination of disability by Social Security. With quicker determinations on the most severe medical cases, claimants have more immediate access to services and support beyond just monetary Social Security disability benefits.

\subsection*{Using CAL Beyond the Initial Claim}

While CAL is designed to expedite the Initial Claim application process, the program can be used at any stage of the administrative process. Most of the time, CAL cases are apparent from the time of filing as the CAL impairment is the reason the claimant

\begin{footnotesize}
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\item \textsuperscript{22} http://ghr.nlm.nih.gov/condition/fibrodysplasia-ossificans-progressiva.
\item \textsuperscript{23} http://www.ncbi.nlm.nih.gov/pubmed/ 1736158.
\item \textsuperscript{24} http://ghr.nlm.nih.gov/condition/perry-syndrome.
\item \textsuperscript{25} http://www.disabilitycanhappen.org/research/CDA_LTD_Claims_Survey_2013.pdf.
\item \textsuperscript{26} http://seer.cancer.gov/statfacts/html/all.html.
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\end{footnotesize}
stopped working in the first instance. However, there are occasions when a claim is filed alleging certain non-CAL impairments, but during the course of the claim, the claimant is diagnosed with one of the CAL impairments. If a claimant develops any of the two hundred CAL impairments after the Initial Claim is filed, the case can still be flagged as a CAL case by DDS or Social Security’s Office of Disability Adjudication and Review.\textsuperscript{27}

In one of our more memorable cases, an individual filed for benefits based on chronic pain assumed to be related to an orthopedic impairment. Tragically, however, the underlying cause of this claimant’s pain was determined to be an inoperable small cell cancer. The diagnosis was made within days of the claimant’s scheduled Social Security disability hearing, and the claimant’s health was rapidly deteriorating. The Administrative Law Judge (ALJ) assigned to the case was not known for his willingness to award cases and wanted a diagnosis confirmed before even thinking about postponing the hearing, let alone awarding the case. Once we submitted medical evidence confirming the new diagnosis of inoperable small cell cancer, a CAL impairment, the ALJ awarded the case. Further, we argued that the claimant’s earlier chronic pain symptoms directly related to the CAL cancer diagnosis, and with the use of a medical expert, we were able to obtain benefits for our client dating back to his original onset date. The framework of the CAL program created the best possible result in a difficult circumstance. The program’s intent to accelerate the processing time prevailed even at the hearing level with a difficult ALJ.

**Implications for the LTD and DI industries**

Just as Social Security is using a predictive model to identify and flag claims which meet CAL diagnostic criteria, sound disability claims practice on the carrier end dictates the early identification of CAL cases. The authors of this paper have provided below a complete, current list of Compassionate Allowance diagnoses. This list is also available on the Social Security Administration website, www.SSA.gov. It is recommended that LTD and DI carriers incorporate this list into an internal predictive model, or employ the services of a vendor with an existing predictive modeling tool which is capable of quickly identifying CAL diagnoses. Prompt action can then be taken to assist claimants through the SSDI process.

**Conclusion**

While CAL has not helped a significantly large number of Social Security claimants, the program is still a step in the right direction. While CAL only benefited 200,000 in the first four years of the program, the statistics show that the number of processed CAL and QDD cases has risen each year. Whereas 173,000 cases were identified as CAL cases in the period between October 2008 and May 2012, nearly 27,000 new CAL cases were processed between June and December 2012 (3,846/month), which indicates that the

\textsuperscript{27} POMS DI 23022.017.
number of identified CAL cases is increasing.\textsuperscript{28} The rise of CAL cases in 2012 is likely attributable to Social Security’s expansion of the program and the addition of more common impairments. Hopefully, Social Security’s CAL team will continue to add more impairments to the CAL list, which will expand the program to more disabled individuals and make CAL a more effective tool for Social Security to provide better and more efficient service.

COMPLETE LIST OF 200 CAL DIAGNOSES

Acute Leukemia  
Adrenal Cancer - with distant metastases or inoperable, unresectable or recurrent  
Adult Non-Hodgkin Lymphoma  
Adult Onset Huntington Disease  
Aicardi-Goutieres Syndrome  
Alexander Disease (ALX) - Neonatal and Infantile  
Allan-Herndon-Dudley Syndrome  
Alobar Holoprosencephaly  
Alpers Disease  
Alpha Mannosidosis - Type II and III  
Alstrom Syndrome  
Alveolar Soft Part Sarcoma  
Amegakaryocytic Thrombocytopenia  
Amyotrophic Lateral Sclerosis (ALS)  
Anaplastic Adrenal Cancer - with distant metastases or inoperable, unresectable or recurrent  
Angelman Syndrome  
Aortic Atresia  
Aplastic Anemia  
Astrocytoma - Grade III and IV  
Ataxia Telangiectasia  
Batten Disease  
Beta Thalassemia Major  
Bilateral Optic Atrophy- Infantile  
Bilateral Retinoblastoma  
Bladder Cancer - with distant metastases or inoperable or unresectable  
Breast Cancer - with distant metastases or inoperable or unresectable  
Canavan Disease (CD)  
Carcinoma of Unknown Primary Site  
Caudal Regression Syndrome - Types III and IV  
Cerebro Oculo Facio Skeletal (COFS) Syndrome  
Cerebrotendinous Xanthomatosis

\textsuperscript{28} http://www.ssa.gov/legislation/testimony_5/17/12.html.
Child Neuroblastoma - with distant metastases or recurrent
Child Non-Hodgkin Lymphoma - recurrent
Child T-Cell Lymphoblastic Lymphoma
Chondrosarcoma - with multimodal therapy
Chronic Myelogenous Leukemia (CML) - Blast Phase
Congenital Lymphedema
Cornelia de Lange Syndrome
Corticobasal Degeneration
Creutzfeldt-Jakob Disease (CJD) – Adult
Cri du Chat Syndrome
Degas Disease - Systemic
DeSanctis Cacchione Syndrome
Dravet Syndrome
Early-Onset Alzheimer's Disease
Edwards Syndrome (Trisomy 18)
Eisenmenger Syndrome
Endometrial Stromal Sarcoma
Endomyocardial Fibrosis
Ependymoblastoma (Child Brain Tumor)
Erdheim Chester Disease
Esophageal Cancer
Ewing Sarcoma
Farber's Disease (FD) – Infantile
Fatal Familial Insomnia
Fibrodysplasia Ossificans Progressiva
Follicular Dendritic Cell Sarcoma - metastatic or recurrent
Friedreichs Ataxia (FRDA)
Frontotemporal Dementia (FTD), Picks Disease -Type A – Adult
Fryns Syndrome
Fucosidosis - Type 1
Fukuyama Congenital Muscular Dystrophy
Fulminant Giant Cell Myocarditis
Galactosialidosis - Early and Late Infantile Types
Gallbladder Cancer
Gaucher Disease (GD) - Type 2
Glioblastoma Multiforme (Adult Brain Tumor)
Glioma Grade III and IV
Glutaric Acidemia - Type II
Head and Neck Cancers - with distant metastasis or inoperable or unresectable
Heart Transplant Graft Failure
Heart Transplant Wait List - 1A/1B
Hemophagocytic Lymphohistiocytosis (HLH) - Familial Type
Hepatoblastoma
Hepatopulmonary Syndrome
Hepatorenal Syndrome
Histiocytosis Syndromes
Hutchinson-Gilford Progeria Syndrome
Hydranencephaly
Hypocomplementemic Urticarial Vasculitis Syndrome
Hypophosphatasia Perinatal (Lethal) and Infantile Onset Types
Hypoplastic Left Heart Syndrome
I Cell Disease
Idiopathic Pulmonary Fibrosis
Infantile Free Sialic Acid Storage Disease
Infantile Neuroaxonal Dystrophy (INAD)
Infantile Neuronal Ceroid Lipofuscinoses
Inflammmatory Breast Cancer (IBC)
Jervell and Lange-Nielsen Syndrome
Junctional Epidermolysis Bullosa - Lethal Type
Juvenile Onset Huntington Disease
Kidney Cancer - inoperable or unresectable
Krabbe Disease (KD) – Infantile
Kufs Disease - Type A and B
Large Intestine Cancer - with distant metastasis or inoperable, unresectable or recurrent
Late Infantile Neuronal Ceroid Lipofuscinoses
Left Ventricular Assist Device (LVAD) Recipient
Leigh’s Disease
Leiomyosarcoma
Lesch-Nyhan Syndrome (LNS)
Lewy Body Dementia
Lissencephaly
Liver Cancer
Lowe Syndrome
Lymphomatoïd Granulomatosis - Grade III
Malignant Brain Stem Gliomas – Childhood
Malignant Gastrointestinal Stromal Tumor
Malignant Germ Cell Tumor
Malignant Melanoma - with metastases
Malignant Multiple Sclerosis
Mantle Cell Lymphoma (MCL)
Maple Syrup Urine Disease
Mastocytosis - Type IV
MECP2 Duplication Syndrome
Medulloblastoma - with metastases
Menkes Disease - Classic or Infantile Onset Form
Merkel Cell Carcinoma - with metastases
Merosin Deficient Congenital Muscular Dystrophy
Metachromatic Leukodystrophy (MLD) - Late Infantile
Mitrval Valve Atresia
Mixed Dementias
MPS I, formerly known as Hurler Syndrome
MPS II, formerly known as Hunter Syndrome
MPS III, formerly known as Sanfilippo Syndrome
Mucocutaneous Malignant Melanoma
Multicentric Castleman Disease
Multiple System Atrophy
Myoclonic Epilepsy with Ragged Red Fibers Syndrome
Neonatal Adrenoleukodystrophy
Nephrogenic Systemic Fibrosis
Neurodegeneration with Brain Iron Accumulation - Types 1 and 2
NFU-1 Mitochondrial Disease
Niemann-Pick Disease (NPD) - Type A
Niemann-Pick Disease-Type C
Nonketotic Hyperglycinemia
Non-Small Cell Lung Cancer - with metastases to or beyond the hilar nodes or inoperable, unresectable or recurrent
Obliterative Bronchiolitis
Ohtahara Syndrome
Ornithine Transcarbamylase (OTC) Deficiency
Orthochromatic Leukodystrophy with Pigmented Glia
Osteogenesis Imperfecta (OI) - Type II
Osteosarcoma, formerly known as Bone Cancer - with distant metastases or inoperable or unresectable
Ovarian Cancer – with distant metastases or inoperable or unresectable
Pancreatic Cancer
Paraneoplastic Pemphigus
Patau Syndrome (Trisomy 13)
Pearson Syndrome
Pelizaeus-Merzbacher Disease-Classic Form
Pelizaeus-Merzbacher Disease-Connatal Form
Peripheral Nerve Cancer - metastatic or recurrent
Peritoneal Mesothelioma
Peritoneal Mucinous Carcinomatosis
Perry Syndrome
Phelan-McDermid Syndrome
Pleural Mesothelioma
Pompe Disease – Infantile
Primary Cardiac Amyloidosis
Primary Central Nervous System Lymphoma
Primary Effusion Lymphoma
Primary Progressive Aphasia
Progressive Multifocal Leukoencephalopathy
Progressive Supranuclear Palsy
Pulmonary Atresia
Pulmonary Kaposi Sarcoma
Retinopathy of Prematurity - Stage V
Rett (RTT) Syndrome
Rhabdomyosarcoma
Rhizomelic Chondrodysplasia Punctata
Roberts Syndrome
Salivary Tumors
Sandhoff Disease
Schindler Disease - Type 1
Severe Combined Immunodeficiency - Childhood
Single Ventricle
Sinonasal Cancer
Small Cell Cancer (of the Large Intestine, Ovary, Prostate, or Uterus)
Small Cell Lung Cancer
Small Intestine Cancer - with distant metastases or inoperable, unresectable or recurrent
Smith Lemli Opitz Syndrome
Spinal Muscular Atrophy (SMA) - Types 0 and 1
Spinal Nerve Root Cancer-metastatic or recurrent
Spinocerebellar Ataxia
Stiff Person Syndrome
Stomach Cancer - with distant metastases or inoperable, unresectable or recurrent
Subacute Sclerosing Panencephalitis
Tabes Dorsalis
Tay Sachs Disease - Infantile Type
Thanatophoric Dysplasia - Type 1
The ALS/Parkinsonism Dementia Complex
Thyroid Cancer
Transplant Coronary Artery Vasculopathy
Tricuspid Atresia
Ullrich Congenital Muscular Dystrophy
Ureter Cancer - with distant metastases or inoperable, unresectable or recurrent
Usher Syndrome - Type I
Walker Warburg Syndrome
Wolf-Hirschhorn Syndrome
Wolman Disease
Xeroderma Pigmentosum
Zellweger Syndrome

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